FORWARD, TOGETHER: ADDRESSING FETAL ALCOHOL SPECTRUM DISORDER (FASD) IN ATLANTIC CANADA

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Gary Roberts and Associates

Prepared for
Public Health Agency of Canada, Atlantic Region
and
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OVERVIEW

Forward, Together: Addressing Fetal Alcohol Spectrum Disorder (FASD) in Atlantic Canada presents the results of a two-phase effort to document FASD in the region; identify gaps, priorities, and opportunities related to FASD-related initiatives; and provide recommendations for future directions for consideration in Atlantic Canada.

The report was commissioned by the Atlantic Region, Public Health Agency of Canada and Health Canada, First Nations and Inuit Health, on behalf of the Atlantic Intergovernmental Fetal Alcohol Spectrum Disorder Partnership, a collaborative forum comprised of representatives of the four Atlantic provincial governments the government of Nunatsiavut, and three departments of the Government of Canada.

Phase I: A Document Review and Synthesis of Information on Fetal Alcohol Spectrum Disorder (FASD) in Atlantic Canada was undertaken and completed in 2007. It documents available information about the incidence and prevalence of FASD in the Atlantic Provinces, calculates its economic cost, examines Atlantic-specific issues associated with FASD and describes the current research and policy milieu.

Phase I's outline of the factors surrounding FASD in the Atlantic Provinces formed the basis for the project's second step, to seek the views of regional stakeholders and their perceptions of gaps, opportunities and priorities related to FASD-related initiatives in Atlantic Canada.

Phase II: The Report of a Knowledge Exchange Process to Identify Gaps, Opportunities, and a Vision for Activities to Address Fetal Alcohol Spectrum Disorder (FASD) in Atlantic Canada presents the results of an intensive information exchange involving regional FASD stakeholders undertaken in early 2008 through both an online survey and focus group sessions.

The Phase II report details stakeholders' perceptions of gaps, challenges, and priorities in policy, programming and research related to FASD-related initiatives in Atlantic Canada. In the course of the knowledge exchange process, stakeholders also identified a number of opportunities to move the issue forward in the short term, contributing to the framing of a vision, developed in the report, suggesting where Atlantic Canada needs to go to strategically and pragmatically address FASD in the region.

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Phase one of this report was prepared by Gary Roberts and Linda Graham. Heather O'Brien conducted the literature and document searches.

The knowledge exchange process and report (phase two) were conducted by a team comprising of Heather O'Brien, Mona Wynn, and Gary Roberts. Heather O'Brien organized the online survey and analyzed the responses. Mona Wynn conceptualized the focus group component, led the English language provincial focus group sessions, and analyzed the focus group session data.
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EXECUTIVE SUMMARY

Fetal Alcohol Spectrum Disorders (FASD), the result of alcohol use during pregnancy, represent a costly and pressing public health and social issue in Atlantic Canada. While preventable, solutions to FASD are complex.

The issue calls for a broad, multi-sectoral strategic response that is underpinned by a strong understanding of the current situation. To this end, this document review and synthesis of information was commissioned by the Atlantic Region of the Public Health Agency of Canada and Health Canada, Atlantic Region - First Nations and Inuit Health on behalf of the Atlantic Intergovernmental FASD Partnership and its FASD Environmental Scan Working Group.

The report documents available information about the nature and scope of FASD in the Atlantic Provinces, the economic impact, factors associated with FASD in the region, and the current research and policy response in Atlantic Canada.

In its examination of the incidence and prevalence of FASD, the report compared the various measurement methods currently in use and reviewed Canadian studies undertaken to date on incidence and prevalence rates. For the purposes of the report, estimates were calculated of the numbers of Atlantic Canadians in 2006 with full Fetal Alcohol Syndrome (FAS) (1,666 to 4,664) and with FASD (23,218).

In assessing the economic costs associated with FASD, the report reviewed American studies and the single Canadian study. It estimated the average annual costs of FASD in Atlantic Canada as being $160,681,786 in 2006, including direct costs (medical, education, social services, out-of-pocket) and indirect costs (productivity losses).

To situate the factors associated with FASD in the Atlantic Region, the report examined knowledge and attitudes concerning the issue on the part of both the general public and health care professionals. It also looked at the awareness and practice of both groups towards alcohol use by women of child-bearing age. Alcohol consumption patterns were also reviewed, focussing on adolescent girls, college and university women, women in Atlantic Canada, pregnant women, and Aboriginal women.

The report includes an assessment of the relationship between the determinants of health and FASD, as well as a discussion of the factors involved in developing a demographic profile of FASD in Atlantic Canada.

The report's investigation of the policy and research response to FASD in Atlantic Canada included both federal and provincial government activity, as well as alcohol-related and FASD-related initiatives. It noted that there is a lack of FASD-specific policies in Atlantic Canada and a dearth of FASD-specific research relevant to the region, two areas warranting further attention.

The report concludes that FASD is an emerging issue in Atlantic Canada. While it offers calculations of the incidence and economic cost of FASD, it suggests that awareness of the human toll and cost extracted by FASD is relatively low. Greater public awareness is needed as to the hazards of binge drinking and rates of unplanned sex while under the influence of alcohol or other drugs. For health care providers, additional knowledge and training in effective clinical practice related to alcohol consumption among women of child-bearing age are identified.

FASD is an issue of vital and timely significance to Atlantic Canada, its mothers, children, families, and communities. The report suggests that the literature it reviewed cannot provide a definitive outline of the realities facing Atlantic Canada in dealing with FASD. An examination of the opportunities and challenges perceived by stakeholders and a review of current FASD activity and programming in the region are critical to further strategic efforts to address this issue.

1. INTRODUCTION

1.1 BACKGROUND

In many ways, the consumption of alcohol is embedded in the culture and traditions of Atlantic Canada. As a commodity, the production and sale of alcohol is very important to the economy of the region, generating profits for manufacturers and advertisers, providing employment in bars and restaurants and producing important tax revenues for governments.[1] From a public health perspective, it is known that small amounts of alcohol (as little as one drink every other day) can bestow cardiovascular benefits when consumed by older persons (men aged 40 and over, women 45 and over).

But due to its capacity to produce intoxication, extensive organ damage and dependence, alcohol is not an ordinary commodity, and the various benefits come at a very high cost to Atlantic Canadians. The World Health Organization ranks alcohol as one of the top five causes of death and disability worldwide,[2] and the costs to the Atlantic Region were estimated to be $1.17 billion in 2002 (New Brunswick: $451M, Nova Scotia: $418.9M, Prince Edward Island: $53.9M, and Newfoundland and Labrador: $246.5M).[3]

Among the more serious harms associated with the consumption of alcohol are Fetal Alcohol Spectrum Disorders (FASD) which are the result of alcohol use during pregnancy.[4] Alcohol as consumed in alcoholic beverages is a teratogen and is a leading cause of birth defects and developmental delay. FASD is preventable; however,

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[1] T.F. Babor, R. Caetano, S. Caswell, G. Edwards, N. Giesbrecht, K. Graham, J. Grube, P. Gruenewald, L. Hill, H. Holder, R. Homel, E. Österberg, J. Rehm, R. Room, and I. Rostow, "Alcohol: No Ordinary Commodity – A summary of the book," *Addiction*, 2003, 98, pp. 1343-1350.

[2] D. Chisholm, J. Rehm, M. Van Ommeren, and M. Monteiro, "Reducing the global burden of hazardous alcohol use: a comparative cost-effectiveness analysis," *Journal of Studies on Alcohol*, 2004, 65, pp. 782-793.

[3] J. Rehm, D. Baliunas, S. Brochu, B. Fischer, W. Gnam, J. Patra, S. Popova, A. Sarnocinska-Hart, and B. Taylor, *The Costs of Substance Abuse in Canada 2002. Highlights*, Canadian Centre on Substance Abuse, Ottawa, 2006.

[4] Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term used to describe the spectrum of disabilities (and diagnoses) associated with prenatal exposure to alcohol. FASD is not itself a diagnostic term; rather, the diagnoses under the FASD umbrella include Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), Alcohol-related Neuro-developmental Disorder (ARND), and Alcohol-related Birth Defects (ARBD).

solutions are complex. Alcohol use during pregnancy is inseparable from many other issues and factors in the lives of mothers, children, their families, and communities.[5]

The past 15 years have seen much progress on this issue in Canada, in terms of both research and response. It is now fully accepted that the issue calls for a broad, multi-sectoral strategic response, and there are a number of examples of this type of activity in Canada. Atlantic Canada has a history of collaboration on many issues, and on this issue efforts are being coordinated by the federal/provincial Intergovernmental FASD Partnership.

This report was commissioned by the Public Health Agency of Canada (Atlantic Region) on behalf of the Atlantic Intergovernmental FASD Partnership and its FASD Environmental Scan Advisory Committee. The purpose of the report is to bring together Atlantic-specific and Atlantic-relevant information that will inform the work of the Partnership and specifically prepare the ground for a more extensive environmental scan. The subsequent scan will explore gaps and opportunities related to prevention, intervention, support, training and education, screening and diagnosis, policies and research activity.

It is intended that this line of activity will lead to the establishment of priorities for FASD initiatives and strategies in Atlantic Canada. A strategic approach is seen as critically important given the complexity of FASD issues, the very broad range of individuals and groups that have a stake in the issues, and the very significant economic and social costs known to be associated with FASD.

Basic to any strategic activity is a strong understanding of the current situation. This report aims to provide that understanding by synthesizing what is known about the nature and scope of FASD in Atlantic Canada, its economic impact, factors associated with FASD in the region, and the current research and policy response in the region.

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[5] G. Roberts and J. Nanson, *Best practices: fetal alcohol syndrome/fetal alcohol effects and the effects of other substance abuse during pregnancy*, Health Canada, Canada's Drug Strategy Division, 2001.

1.2 METHODOLOGY

Several fairly distinct literatures were searched to gather and synthesize the necessary information.

1.2.1 Incidence and prevalence rates and economic and social costs of FASD in Atlantic Canada

Peer literature databases searched: PUBMED, Digital Dissertations, Psyc INFO, Psyc Articles, Soc Index, CINAHL.

Subject areas covered: medicine, nursing, health, psychology, sociology.

From the more than 500 articles identified, 199 were considered to be generally relevant. Titles and abstracts were scanned, and 37 articles that dealt specifically with the estimation of incidence, prevalence, or economic costs of FASD were selected for review.

1.2.2 Knowledge, attitudes, and behaviours associated with FASD specific to Atlantic Canada

Keywords: FAS, FASD, education levels, income, income disparity, socioeconomic status, early child development, genetic factors, lifestyle, alcohol, pregnancy, health determinants.

A search was made of the Dalhousie University (a national government document depository) catalogue for provincial and federal government documents and statistical databases for surveys related to FASD or determinants of health in the region. Also searched were the Canadian Centre on Substance Abuse Library Collection Database, Centre for Addiction and Mental Health Library Database, and library databases (where they existed) of the Atlantic provincial departments of health and the Atlantic Centre of Excellence for Women's Health.

Twenty three documents were identified as relevant to the review.

1.2.3 Existing research on FASD in Atlantic Canada

Searched were the web sites of national funding bodies, including the Social Sciences and Humanities Research Council (SSHRC), National Sciences and Engineering Research Council (NSERC), and the Canadian Institutes of Health Research (CIHR); regional organizations, including the Atlantic Health Promotion Institute; and provincial research funding bodies, including the Nova Scotia Health Research

Foundation, Newfoundland and Labrador Centre for Applied Health Research, and the Prince Edward Island Health Research Institute, to identify current research on FASD. Working group members who were familiar with particular studies were contacted.

Forty seven research projects viewed as having possible broad relevance to the issue were identified (i.e., included research on various determinants of health). The projects were narrowed to 14, representing published research and research in progress that were perceived as more closely relevant to FASD in the region. Since many of these research projects had not reported findings, the principal investigators were contacted and asked if they perceived their research to be of relevance to FASD in the region. This elicited a response from two researchers. Seven research articles, specifically focussed on FASD or hazardous alcohol use by women (including the work of the two responding researchers), are summarized in this report.

1.2.4 Existing policies (federal and provincial) relevant to FASD in Atlantic Canada

For the purposes of this report, policy is defined as "A statement that provides direction or guidance to organizations, associations, or governments at the federal, provincial, or municipal levels on FASD (that is, it explicitly mentions FASD, alcohol-exposed pregnancy or alcohol use by women in child-bearing years)."

Keywords: policy, policies, position, FASD, FAS, early childhood, alcohol, alcohol-exposed pregnancy, alcohol use by women.

Information on existing policies from Partnership members and stakeholders was sought when they were contacted for the stakeholder's database. Just two mentions of a FASD-relevant policy were provided through this step. A recent review of relevant policies by Jennifer Clinesmith, *Children and youth with special needs: A review of federal, provincial and territorial legislation, policy and programs*, became a major reference.[6] While noting a dearth of FASD-specific policies in Atlantic Canada, this report provided a good review of federal policies and strategies on FASD. Through a scan of various web sites, several other broadly relevant policy-related initiatives were identified.

Further detail on the search methodology for each of the four searches is available on request from the authors.

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[6] J. Clinesmith, *Children and youth with special needs: A review of federal, provincial and territorial legislation, policy and programs*, Centre of Excellence for Children and Adolescents with Special Needs and UNBC Task Force on Substance Abuse, no date.

1.3 TERMINOLOGY

FASD is an umbrella term now used to describe the spectrum of disabilities (and diagnoses) associated with prenatal exposure to alcohol. FASD is not itself a diagnostic term; rather the diagnoses under the FASD umbrella include the following, as defined by the U.S. Institute of Medicine (1996):[7]

- Fetal Alcohol Syndrome (FAS): confirmed history of maternal alcohol exposure requiring evidence of facial dysmorphology, growth retardation and central nervous system (CNS) dysfunction;
- partial FAS (pFAS): a confirmed history of prenatal alcohol exposure, facial dysmorphology and either growth retardation or central nervous system (CNS) abnormalities;
- Alcohol-related Neuro-developmental Disorder (ARND): a confirmed history of prenatal alcohol exposure and evidence of CNS abnormalities;
- Alcohol-related Birth Defects (ARBD): the presence of congenital anomalies (e.g., cardiac, skeletal, renal, ocular, auditory) known to be associated with a history of prenatal alcohol exposure.

The term, Fetal Alcohol Effects (FAE), used by some sources in this report referred to effects other than full FAS and has been replaced by the term partial FAS.[8]

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[7] Public Health Agency of Canada, *Fetal alcohol spectrum disorder (FASD): a framework for action*, Government of Canada, 2003.

[8] Roberts et. al., op. cit.

2. SCOPE AND IMPACT OF THE PROBLEM IN ATLANTIC CANADA

2.1 ESTIMATED INCIDENCE AND PREVALENCE OF FASD

In the FASD literature, the terms incidence and prevalence are used almost interchangeably. Generally, incidence in epidemiology refers to new cases and prevalence to all new and existing cases within a given time frame. Since fetal effects begin in the gestational period, some believe that spontaneous abortions by alcohol-involved women lower the incidence rate of FAS at birth; hence prevalence rates are used by many researchers for all age groups.[9] Most studies focus on the prevalence of full FAS because the criteria for diagnosis are more specific, making estimation easier than for the other conditions in the spectrum.[10]

This review is organized first by outlining the principal methods used to determine incidence and prevalence of FAS. In each of the method sections, leading examples of the methodology are reviewed, and advantages and limitations to the methods are described. Excluded from this review are the specific criteria used in each of the studies for case identification. Included are a number of expert review articles that have been written critiquing the various methods employed to estimate prevalence of FASD. Following the methods section, a summary drawn from two of these review articles describes the basic criteria needed to determine FAS prevalence and maternal risk factors for FAS. Canadian incidence and prevalence studies are then described, followed by recommendations for estimating prevalence in Nova Scotia.

2.1.1 Methods

The principal methods used to determine the incidence and prevalence for FASD are passive surveillance, clinic-based studies and active case ascertainment. Each of these methods has their strengths and limitations.

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[9] P.A. May and J.P. Gossage, "Estimating the prevalence of Fetal Alcohol Syndrome," *Alcohol Research & Health*, 2001; 25(3), pp. 159-167.

[10] P.D. Sampson, A.P. Streissguth, F.L. Bookstein, R. E. Little, S.K. Clarren, P. Dehaene, J.W. Hanson, and J.M. Graham, "Incidence of Fetal Alcohol Syndrome and Prevalence of Alcohol-related Neurodevelopmental Disorder," *Teratology*, 1997, 56, pp. 317-326.

Passive surveillance

The largest passive surveillance projects for FAS are administered by the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia. The original CDC program for FAS surveillance was based solely on the Birth Defects Monitoring Program (BDMP).[11] Non-federal, short-term-stay hospitals voluntarily contribute newborn hospital discharge data to the BDMP. In 1993, the rate for FAS was 6.7 per 10,000 live births, a fourfold increase since 1979 (1.0 per 10,000 births). This rate was based on 5% of United States births in 1993, compared to the 30% of births used to estimate the 1979 rate. The data are collected from the ICD-9CM discharge code 760.71 which is not specific for FAS but refers to any alcohol-related condition.

In another CDC initiative, a multiple-source method linking the Metropolitan Atlanta Congenital Defects Program (MACDP) and the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) was used to estimate the prevalence of FAS in a defined population (five metropolitan Atlanta counties) from 1981-1989.[12] This method is superior to using only birth records, as most FAS cases are diagnosed after age 6. In this approach, data were abstracted from all maternity hospitals, neonatal intensive care units and genetic clinics in the area. In addition, records were abstracted for children attending public special education schools and for those receiving specialty services. The observed prevalence was 1.0 case per 10,000 live births and 2.5 cases per 10,000 for both full and partial FAS. Capture-recapture analysis was used to assess the completeness of case ascertainment. The estimated prevalence using capture-recapture methodology was 1.6 cases per 10,000 for full FAS and 5.1 cases per 10,000 for full and partial FAS.

In 1997, the CDC introduced the Fetal Alcohol Syndrome Surveillance Network (FASSnet).[13] Funds were made available to five states over a five-year period to use multiple-source (Alaska, Arizona, Colorado and New York) or alternative methodology (Wisconsin) to determine prevalence rates for FAS. Standardized case definitions and criteria were developed. The multiple-source method used by four of the states resulted in a sample of 145,730 live births for the period 1995-1997. The study population was made up of 62% white children, 23% Hispanic, 6% Black, 6% Native, and 2% Asian. The FASSnet program used both passive surveillance and active record abstraction to

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[11] Centers for Disease Control and Prevention, "Update: Trends in Fetal Alcohol Syndrome – United States, 1979-1993," *Morbidity and Mortality Weekly Report*, 1995, 44(13), pp. 249-251.

[12] Centers for Disease Control and Prevention, "Surveillance for Fetal Alcohol Syndrome using multiple sources – Atlanta, Georgia, 1981-1989," *Morbidity and Mortality Weekly Report*, 46(47), pp.1118-1120.

[13] K. Hymbaugh, L.A. Miller, C.M. Druschel, D.W. Podvin, F.J. Meaney, and C.A. Boyel, "The FASSnet Team. A multiple source methodology for the surveillance of Fetal Alcohol Syndrome – The Fetal Alcohol Syndrome Surveillance Network (FASSnet)," *Teratology*, 2002, 66, pp. S41-S49.

populate the database. Data sources included the BDMP, hospital discharge data, genetics, developmental and neonatology clinics, private physicians, state Medicaid programs, early intervention programs, vital records and other sources. Due to the limited time period, only younger children with FAS (< 2 years of age) were identified. The FAS rate for these four states for children born from 1995-1997 was 0.3 to 1.5 per 1,000 live births.[14] Rates were highest for Black (0.9-1.6 per 1,000) and American Indian/Alaska Native (2.5-5.6 per 1,000) children. Results were based on 1,489 births during the time period. A total of 185 children met the case criteria for confirmed or probable FAS.

Feasibility is the major advantage to passive surveillance systems as existing data sources are used, resulting in lower estimation costs.[15] Limitations to passive registries are that the children are not examined to confirm the diagnosis, cases are only identified if diagnosed and documented in records, children may not be captured due to loss to follow-up or death, and many children are not diagnosed until they reach school age.[16] [17] [18] In a New York study that compared the completeness and validity of a birth defects registry for estimating the rate of FAS to FASSnet, it was found that only 58% (19/33) of FAS cases from the birth registry met FASSnet criteria for FAS. The FASSnet program identified 24 additional cases.[19] FAS prevalence using only the birth registry gave a rate of 0.28 per 1,000 live births compared to 0.37 if all children diagnosed before 2 years of age were included using the FASSnet methodology.

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[14] Centers for Disease Control and Prevention, "Fetal Alcohol Syndrome – Alaska, Arizona, Colorado, and New York, 1995-1997, *Morbidity and Mortality Weekly Report*, 2002, 51(20), pp. 433-435.

[15] May et. al., "Estimating the prevalence of Fetal Alcohol Syndrome," op. cit.

[16] J.F. Cordero, R.L. Floyd, M.L. Martin, M. Davis, and K. Hymbaugh, "Tracking the prevalence of FAS," *Alcohol Health and Research World*, 1994, 18(1), pp. 82-85.

[17] Centers for Disease Control and Prevention, "Surveillance for Fetal Alcohol Syndrome using multiple sources – Atlanta, Georgia, 1981-1989," op.cit.

[18] Centers for Disease Control and Prevention, "Fetal Alcohol Syndrome – Alaska, Arizona, Colorado, and NewYork, 1995-1997," op. cit.

[19] D.J. Fox and C.M. Druschel, "Estimating the prevalence of Fetal Alcohol Syndrome (FAS): Effectiveness of a passive birth defects registry system. Birth Defects Research (Part A)," *Clinical and Molecular Teratology*, 2003, 67, pp. 604-608.

Clinic-based studies

Clinic-based studies are generally conducted prospectively by following women in prenatal clinics.[20] The design of these studies is fairly rigorous and offers good insight into maternal history; however, the women are self-selected, and many high-risk mothers do not attend prenatal clinics regularly, or at all. In addition, most clinic-based studies in the United States are carried out in publicly-funded institutions that cater to disadvantaged populations; therefore, the findings are not representative of the population as a whole.

In 1991, Abel and Sokol estimated the incidence of FAS in the "western world" (based on 31 prospective studies from Australia/New Zealand, Sweden, the United Kingdom, United States and Canada) at 0.33 cases per 1,000.[21] This was a decrease from their previous estimate of 1.9 per 1,000 in 1987. The principal reason for the lower rate is the exclusion of retrospective studies used in the 1987 estimate that may have resulted in many false positives. The 1991 FAS rates estimated by Abel and Sokol ranged from 0 to 4.7 per 1,000 depending on the study population's ethnic and socio-economic (SES) background. Abel and Sokol determined that rates of FAS were highest among low SES, Black, and Native populations.

In 1995, Abel revised the worldwide incidence rate to 0.97 cases per 1,000 live births, based on 35 prospective studies and the United States rate at 1.95 per 1,000.[22] The rates ranged from 0 to 3.9 per 1,000 live births. According to Abel, the most critical risk factors for FAS were the country of study and low SES, and not race as previously thought. Although Abel discounted the impact of heavy drinking on prevalence for FAS, he did concede that the effect of heavy drinking was difficult to assess because of the different definitions of heavy drinking worldwide. Critics of Abel and Sokol's estimates believe that pooling of worldwide data is not valid as the sample sizes, case finding and case definitions vary too widely.[23]

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[20] May et. al., "Estimating the prevalence of Fetal Alcohol Syndrome," op. cit.

[21] E.L.Abel and R.J. Sokol, "A revised conservative estimate of the incidence of FAS and its economic impact," *Alcoholism: Clinical and Experimental Research*, 1991, 15(3), pp. 514-524.

[22] E.L. Abel, "An update on incidence of FAS: FAS is not an equal opportunity birth defect," *Neurotoxicology and Teratology*, 1995, 17(4), pp. 437-443.

[23] Sampson et. al., op. cit.

Active case ascertainment

In this method, potential FAS children are screened for and examined in a specific geographical area.[24] Clinical experts seek out potential FAS children at appropriate ages for diagnosis. By applying a very comprehensive outreach population approach, this method has a higher probability of identifying FAS children and high-risk mothers than other methods. In addition, because whole communities are surveilled, this approach is more representative of a population and has the highest chance of achieving an accurate rate of prevalence.[25]

A few large ascertainment studies have been carried out worldwide. In Washington State, all elementary schools in two counties were asked to participate in a screening, diagnosis and treatment project for FAS.[26] In one county (A), all schools agreed to participate except one small private school. Passive consent was used, resulting in almost 100% participation (n=1630). The racial background for County A was 85% white and 10% Native American. In County B, active parental consent was required, resulting in only a 25% participation rate. Participating first grade students were initially screened by trained public health nurses. Children were referred to a special diagnostic clinic if they were below the 10th percentile for height and/or weight with at least one facial feature of FAS; if they had more than one facial feature of FAS and behavioural and developmental problems consistent with FAS; or if school records indicated prenatal alcohol exposure and school staff or families requested assessment. Sixty-three students screened positive, and 36 families agreed to the clinic exam from County A. Clinic examinations for FAS conducted by a dysmorphologist, psychologist and public health nurse identified five full FAS cases. The minimal prevalence of FAS in County A was 3.1 per 1,000 students. The prevalence was not determined in County B due to poor participation.

In a South African community, 93.6% of first grade children received parental consent for initial screening of height, weight and occipitofrontal head circumference (OFC) to determine prevalence of FAS.[27] If a child was below the 10th percentile in OFC and/or both height and weight, a referral for a complete physical examination was made. A control group of children was selected randomly from non-FAS students to receive the

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[24] May et. al., "Estimating the prevalence of Fetal Alcohol Syndrome," op. cit.

[25] Ibid.

[26] S.K. Clarren, S.P. Randels, M. Sanderson, and R.M. Fineman,"Screening for Fetal Alcohol Syndrome in primary schools: A feasibility study," *Teratology*, 2001, 63, pp. 3-10.

[27] D.L. Viljoen, J.P. Gossage, L. Brooke, C.M. Adnams, K.L. Jones, L.K. Robinson, H.E. Hoyme, C. Snell, N.C.O. Khaole, P. Kodituwakku, K.O. Assante, R. Findlay, B. Qunitan, A.S. Marais, W.O. Kalberg, and P.A.May, "Fetal Alcohol Syndrome epidemiology in a South African community: A second study of a very high prevalence area," *Journal of Studies on Alcohol*, 2005, 66, pp. 593-604.

same battery of examinations and tests for comparison. Sixty-four children were diagnosed with FAS, yielding the highest reported prevalence rate worldwide at 65.2 to 74.2 per 1,000 first grade children. Mothers of FAS children reported drinking more at the time of the study, mostly on weekends. Most of the mothers (92.3%) reported drinking during the pregnancy and were more likely than controls to live in rural communities. Fathers were also found to be heavy drinkers.

In Italy, 25 primary schools were chosen randomly from two health districts to participate in a study to examine the prevalence of FAS in a culture where moderate daily drinking was believed to be the norm.[28] Fifty percent of first grade children from the selected schools (n=543) received permission to be screened and were sent for a diagnostic evaluation that included maternal interviews, physical examinations and psychological and developmental assessments. A control group (n=75) was selected from among those children with parental consent to participate in the study. Diagnoses were made by the entire research team at a case conference. Four children were diagnosed with FAS, 17 with pFAS, and one child with ARND. Four diagnoses were deferred due to lack of follow-up. The prevalence for FAS for this Italian province was 3.7 to 7.4 per 1,000 children (the rate range reflects the 50% participation rate). The prevalence of FASD was estimated at 20.3 to 40.5 per 1,000 children or 35 per 1,000 overall (2.3 to 4.1% of all children). Self-reported current drinking rates of mothers of children with FASD were significantly higher than control mothers; however, reported drinking during pregnancy was not significantly different. Contrary to the study hypothesis, mothers in the experimental group did not drink on a daily basis. Drinking in the second and third trimesters, drinks per current drinking day and monthly current drinking were all significantly correlated with the children's dysmorphology scores.

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[28] P.A. May, D. Fiorentino, J.P. Gossage, W.O. Kalberg, H.E. Hoyme, L.K. Robinson, G. Coriale, K.L. Jones, M. del Campo, L. Tarani, M. Romeo, P.W. Kodituwakku, L. Deiana, D. Buckley, and M. Ceccanti, "Epidemiology of FASD in a province in Italy: Prevalence and characteristics of children in a random sample of schools," *Alcoholism: Clinical and Experimental Research*, 2006, 30(9), pp. 1562-1575.

2.1.2 Basic elements for determining prevalence of FAS and maternal risk factors for FAS

Studying a specific population over a given time period using well-defined criteria are the two principal requirements in determining FAS incidence.[29] The population must include all live infants rather than only those of high-risk groups. To accurately diagnose FAS, potential characteristics must be assessed by trained clinicians in their entirety and not singly. Furthermore, "a representative sample of an entire cohort must be examined" between ages 8 months and 8 years to avoid age-related changes to criteria.[30]

In 2001, May and Gossage reviewed the study methods and rates thus far for FAS, concluding that the passive surveillance methods rates were too low and that clinic-based and active case ascertainment methods yield higher rates.[31] These researchers postulated that averaging the clinic-based (0.26-2.29 per 1,000 births) and active case ascertainment findings (1.4-9.8 per 1,000 births) would give a falsely high rate not reflective of the general United States population as many of these studies are conducted in high-risk groups. They estimated the prevalence of FAS at 0.5-2.0 per 1,000 births in the United States and a rate of 10 per 1,000 births (1%) or more for all measurable effects (FAS, ARBD, and ARND) of prenatal alcohol exposure. They listed the maternal health risk factors for FASD as older maternal age (>25 years), having three or more children, multiple substance use and morbidity and premature mortality from alcohol-related causes. They identified social risk factors for FAS as including low SES, frequent and prolonged binge drinking and cultures permissive of heavy or problem drinking. Low self-esteem, depression, abuse and violence-related trauma and sexual dysfunction were cited as the psychological characteristics of the mothers of FAS children.

2.1.3 Canadian studies

A number of studies investigating the prevalence of FAS have been conducted in western Canada. The majority of these studies were conducted among high-risk and/or Aboriginal populations.

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[29] Sampson et. al., op. cit.

[30] Ibid.

[31] May et. al., "Estimating the prevalence of Fetal Alcohol Syndrome," op. cit.

Saskatchewan study[32]

In this study, incidence of FAS was determined in Saskatchewan by identifying all known cases at the two provincial treatment centres and contacting all health professionals who may have encountered FAS individuals in their practice. Researchers compared the incidence of FAS over a 20-year span to gauge the impact of educational initiatives implemented over that time to prevent FAS.

The incidence of FAS was 0.515 per 1,000 live births in 1973-77 and 0.589 per 1,000 in 1988-92. No educational effect was observed. A limitation to this approach is the potential to underestimate incidence due to the failure to capture all cases, particularly the undiagnosed. During the study time period, 12 deaths from FAS were observed, and 72% of diagnosed children were found to have a skeletal or cardiac anomaly or other malformation. The mean IQ for children with FAS was 67.8. Almost half (45.9%) had significant psychosocial problems, and only 25% were in a regular classroom unassisted. Most were not living at home (74.4%), and 72% had spent some time in a foster home.

Aboriginal studies in British Columbia and Yukon

A number of older studies among Canadian Aboriginal people in British Columbia and Yukon have shown high prevalence rates for FAS and/or FAE from 25 to 190 per 1,000 live births.[33] One study conducted in two Vancouver hospitals reported the ratio for FAS children among Aboriginal people to be 10.9 times higher than for Caucasian children.[34] The sampling frames for these studies varied from hospitals (Vancouver), referrals from community agencies (Yukon and northwest British Columbia) and a British Columbia First Nation reserve.

A number of methodological flaws were found in each of these studies: none of the studies accounted for potential confounders or used comparison groups; some of the intelligence testing may have been biased against Aboriginal and/or rural children; in addition, the facial feature assessment criteria used in these studies was based on United States Caucasian features and thus may not be particularly relevant for all ethnic

[32] B.F. Habbick, J.L. Nanson, R.E. Snyder, R.E. Casey, and A.L. Schulman, "Foetal Alcohol Syndrome in Saskatchewan: Unchanged incidence in a 20-year period," *Canadian Journal of Public Health*, 1996, 87(3) pp. 204-207.

[33] D.L. Bray and P.D. Anderson, "Appraisal of the epidemiology of Fetal Alcohol Syndrome among Canadian Native peoples," *Canadian Journal of Public Health*, 1989, 80, pp. 42-45.

[34] Roberts et. al., op. cit.

groups; and the growth charts used to assess height and weight were also United States-based and again may not be directly applicable to the Canadian population.[35]

Northern Manitoba[36]

To determine FAS incidence in northeastern Manitoba in this study, all birth records for 1994 were reviewed in Thompson General Hospital against broad criteria to capture potential FAS cases. Out of 745 live births, 192 met the initial screening requirements for FAS. Two years later (1996), patient record information was screened a second time to assess for potential cases. From the 192 potential cases, 96 children met the secondary screening criteria. Of these cases, 41 children were examined for signs of growth retardation, developmental delay and facial abnormalities. The other 43 children were either not located, permission not granted for examination, or they lived in too remote an area. From these 41 cases, five children were diagnosed with FAS, giving an incidence rate of 7.2 per 1,000 live births. These findings were likely an underestimate for the region, as less than half of the potential cases were examined, and 43% of infants (usually high-risk deliveries) in the area were delivered in Winnipeg hospitals.

British Columbia FAS youth in criminal justice system[37]

In this study, all youths aged 12 to 18 years remanded in a one-year period to an inpatient assessment unit for youth criminals in Burnaby, British Columbia were examined for FAS/FAE. One per cent (n=3) of the youths were diagnosed with FAS and 22.3% (n=64) with FAE. Only three of the 67 youths were diagnosed prior to remand. It should be noted that this sample was remanded to a forensic psychiatric assessment and thus should not be viewed as representative of all youth in the juvenile justice system.

2.1.4 FASD Canadian Guidelines[38]

A subcommittee of the Public Health Agency of Canada's National Advisory Committee on Fetal Alcohol Spectrum Disorder led by Dr. Albert Chudley reviewed, analysed and integrated current approaches to diagnosis to reach agreement on a

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[35] Ibid.

[36] R.J. Williams, F.S. Odaibo, and J.M. McGee, "Incidence of Fetal Alcohol Syndrome in Northeastern Manitoba, *Canadian Journal of Public Health*, 1999, 90, pp. 192-194.

[37] D.K. Fast, J. Conry, and C.A. Loock, "Identifying Fetal Alcohol Syndrome in the Criminal Justice System," *Developmental and Behavioral Pediatrics*, 1999, 20(5), pp.370-372.

[38] A.E. Chudley, J. Conry, J.L. Cook, C. Loock, T. Rosales, and N. LeBlanc, "Fetal Alcohol Spectrum Disorder: Canadian guidelines for diagnosis," *Canadian Medical Association Journal*, 2005, 172(5 suppl.), pp. S1-S21.

standard in Canada. The Committee noted that, although rates for specific areas have been calculated (see above), national incidence and prevalence rates for Canada are unknown because these local rates cannot be generalized to the Canadian population as a whole.

The Committee noted that maternal alcohol consumption is the most significant risk factor for FASD, primarily related to the timing, pattern (e.g., binge drinking – four or more drinks at a sitting) and frequency of use during pregnancy. (Canadian drinking rates during pregnancy have decreased over time. According to the 1994-95 *National Population Health Survey* and *National Longitudinal Survey of Children and Youth*, 17-25% of women reported some alcohol use during pregnancy, compared to 14.4% of women in the 1998-99 *National Longitudinal Survey of Children and Youth.*)

A broad consultation process undertaken by the Committee revealed that there was inadequate diagnostic capacity in Canada, resulting in many individuals being denied access to diagnosis. Limited resources and "uni-disciplinary" diagnoses characterized this inadequacy. Clinical geneticists were reluctant and unequipped to diagnose the full spectrum of the disorder, and it was clear that no single diagnostic approach was being used. The consultation also revealed a disparity in diagnostic capacity across the country. The Committee emphasized that much improved national capacity for diagnosis based on a comprehensive multidisciplinary assessment is required to determine accurate incidence and prevalence rates for FASD in Canada.[39]

2.1.5 Recommendations for estimation of FASD rates in Atlantic Canada

In general, the Canadian studies of incidence and prevalence of FASD cannot be directly applied to the Atlantic Canadian population as most of the studies, except for the Saskatchewan study, were conducted in high-risk communities. Some Canadian literature makes reference to a rate of 1 infant per 100 born with FASD or 3,000 infants born per year in Canada.[40] [41] Other studies cite 4,000 infants a year or 1-6 in 1,000 live births.[42] [43] However, the authors using these rates do not refer to any specific studies or data on which to base these estimates. Therefore, based on this review of the literature,

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[39] Public Health Agency of Canada and Canadian Centre on Substance Abuse, *Summary Report: National Forum on the FASD Diagnostic Guidelines*, Public Health Agency of Canada, Ottawa, 2005.

[40] J. Hutson, "A prenatal perspective on the cost of substance abuse in Canada," *Journal of FAS International*, 2006, 4, pp. 1-4.

[41] Healthy Ontario, *Get off the FAS track*, www.healthyontario.com

[42] C. McLean, "The fetal alcohol crisis," *The Report NewsMagazine*, September 25, 2000.

[43] B. Stade, W.J. Ungar, B. Stevens, J. Beyene, and G. Koren, "The burden of prenatal exposure to alcohol: Measurement of cost," *Journal of FAS International*, 2006, 4, pp. 1-14.

the findings of Chudley et. al.[44] are viewed as most credible; that is, at present, there is no known prevalence rate that can be applied to the overall Atlantic Canada population to determine an accurate estimate for FAS.[45]

- To determine a prevalence estimate for Atlantic Canada, ideally an active case ascertainment study should be conducted in the provinces using the sampling method employed in the Italian study. This method should capture the majority of school-aged children with FASD except those who are not attending public school (e.g., severely handicapped children, home-schooled children and children attending private school). Prevalence studies in populations known to be at higher risk, such as children in foster care or young offenders, would also be helpful.

- If an estimate is required over the short term for planning or other purposes, the overall United States-based rates by May and Gossage[46] of 0.5-2.0 per 1,000 births for FAS and 10 per 1,000 births (1%) for all effects of prenatal alcohol exposure are viewed as most credible and applicable to Atlantic Canada.[47]

2.1.6 FASD estimates for Atlantic Canada

Previously in Atlantic Canada, estimates for FASD have been determined by applying internationally recognized rates. Smith and Rosales[48] used the rates of 0.33 to 0.97 cases per 1,000 live births to calculate FAS prevalence at 187 to 551 persons and 9.1 cases per 1,000 for ARND and FAS, yielding an estimated total of 5,173 cases in Newfoundland and Labrador in 1999. In the Atlantic FAS/FAE Tool Kit,[49] the rate of one to three live births was used to estimate prevalence for FAS and 9.1 per 1,000 for all disabilities from prenatal alcohol exposure in Atlantic Canada in 2003. By applying these rates, it was calculated that 2,300 people in Atlantic Canada had FAS and 20,800 FAE in 2003.

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[44] Chudley et. al., op. cit.

[45] Ibid.

[46] May et. al., "Estimating the prevalence of Fetal Alcohol Syndrome," op. cit.

[47] Without a Canadian estimation, this one, developed for the United States government, is viewed as the best available. While caution needs to be applied to the use of any United States rates in Canada, there is some basis for comparability in this case because alcohol use rates among women of child-bearing age are similar in the two countries.

[48] N. Smith and T.O. Rosales, *FAS and FAE: A report on prevalence and prevention activities in Newfoundland and Labrador*, authors, St. John's, 1999, p. 12.

[49] Health Canada, *FAS/FAE Information Tool Kit*, Population and Public Health Branch, Atlantic Regional Office, and First Nations and Inuit Health Branch, Atlantic Regional Office, Halifax, 2003.

In 1998-99, Cox and Dickinson[50] conducted an active case ascertainment study in an Aboriginal community in New Brunswick, screening 187 children in Grades 1-8 over a two-year period. They established that 19.4% of the children had either FAS, pFAS, or ARND, based on the U.S. Institute of Medicine criteria. The authors noted that while all of the children identified were born in the late 1980s and 1990s in a large regional hospital where many of the mothers accessed prenatal services, none of the cases was diagnosed at birth.

To update these general population estimates for the purposes of this review and synthesis of information, the May and Gossage[51] rates of 0.5-2.0 per 1,000 births for FAS and 10 per 1,000 births (1%) for all effects of prenatal alcohol exposure were applied to population estimates for Atlantic Canada. By applying these rates to the average number of births annually for the five-year period July 2001 to June 2006 (n=21,558),[52] we estimate that 11 to 43 infants were born with FAS, and a total of 216 infants were born with any effects from prenatal alcohol exposure in each of those years in Atlantic Canada.[53]

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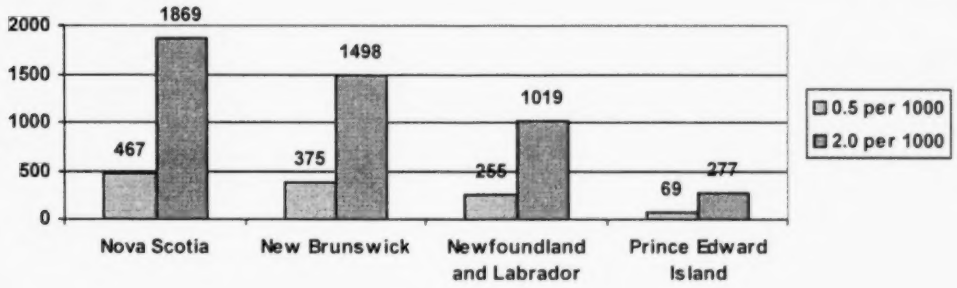
[50] L.V. Cox and M. Dickinson, *The prevalence of FASD in a Maritime First Nations Community*, FACE research round table web cast presentation, September 8, 2006, Moncton, New Brunswick, www.motherisk.org/JFAS/econtent_commonDetail.jsp?econtent_id=126

[51] May et. al., "Estimating the prevalence of Fetal Alcohol Syndrome," op. cit.

[52] The number of births for 2004/2005 are revised, and 2005/2006 are preliminary estimates from Statistics Canada CANSIM tables.

[53] Statistics Canada, *CANSIM tables. Births and birth rate, by province and territory*, www40.statcan.ca/101/cst01/demo31a.htm

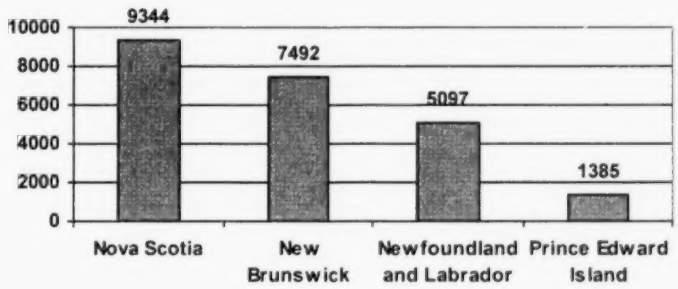
Figure 1 Estimated number of people living with FAS in Atlantic Provinces, 2006



We estimate that in 2006 in Atlantic Canada, anywhere from 1,166 to 4,664 people had full FAS, and 23,318 people had an FASD.[54] Figure 1 shows the potential number of people with FAS in each of the Atlantic Provinces, depending on the prevalence rate applied.

Figure 2 displays our estimate of the number of people in each of the Atlantic Provinces with FASD. It is important to remember that these are estimates and until a study has been completed in the Atlantic Provinces, or in another population similar to the region, the accuracy of these numbers is unknown.

Figure 2 Estimated number of people living with a FASD in Atlantic Provinces, 2006



[54] Statistics Canada, *CANSIM tables. Population by sex and age group, by province and territory.* www40.statcan.ca/101/cst01/demo04a.htm

2.2 ESTIMATED ECONOMIC COSTS ASSOCIATED WITH FASD

In this section, American cost estimate studies will be summarized followed by a more extensive review of the lone Canadian study.

A number of economic studies and updates to these studies have been conducted in the United States. Abel and Sokol first calculated the economic cost of FAS in 1984 at $321 million US a year based on prevalence estimates of 1.9 per 1,000 live births.[55] These figures were updated in 1987 to $74.6 million per year based on a lower prevalence rate of 0.33 per 1,000 live births.[56] These estimates were determined only for cases of full FAS, and included treatment and residential costs up to age 21 only. Abel and Sokol's estimate of costs for care in 1987 was $250 million/year.[57] The increased costs were the result of higher prevalence rates of low birth weight FAS infants and included living costs (housing and food) for all FAS children and not just those in institutional care. None of these estimates included costs for lost productivity, semi-independent community care, and/or residential care for the mentally handicapped after 21 years of age.

Rice and colleagues estimated the economic cost of FAS at $1.611 billion in 1985.[58] This estimate was based on Abel and Sokol's FAS prevalence estimate of 1.9 per 1,000 live births. Included in this estimate were costs for neonatal intensive care, all treatment and care to age 21 years and residential care for the mentally handicapped after age 21. These estimates were later updated in 1990 to $2.089 billion to reflect a population increase and higher health care costs.[59]

Economic costs are much higher if lost productivity estimates are included. Harwood and Napolitano estimated the economic cost of FASD at $3.235 billion in 1980 based on a prevalence estimate of 1.67 per 1,000 live births. In 1992, Harwood and colleagues estimated the cost at $2.934 billion based on a prevalence rate of 2.0 per 1,000 live births. This estimate was updated in 1998 to $4.022 billion. These estimates included

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[55] E.L. Abel and R.J. Sokol, "Incidence of fetal alcohol syndrome and economic impact of FAS-related anomalies, *Drug and Alcohol Dependence*, 1987, 19(1), pp. 51-70.

[56] Abel et. al., "A revised conservative estimate of the incidence of FAS and its economic impact," op. cit.

[57] C. Lupton, L. Burd, and R. Harwood, "Cost of Fetal Alcohol Spectrum Disorders, *American Journal of Medical Genetics*, 2004, 127C, pp. 42-50.

[58] D.P. Rice, S. Kelman, and L.S. Miller, "Estimates of economic costs of alcohol and drug abuse and mental illness, 1985 and 1988," *Public Health Reports*, 1991, 106(3), pp. 280-292.

[59] M.G. Klug, and L. Burd, "Fetal alcohol syndrome prevention: annual and cumulative cost savings," *Neurotoxicology and Teratology*, 2003, 25, pp. 763-765.

treatment and care services up to 21 years, home and residential care for those with moderate to severe mental handicaps to 65 years, special education services and lost productivity. Later updates in costs were made to reflect changes in health care costs, consumer price index for medical services, population and compensation for lost productivity.[60]

The annual cost of FAS care per individual with full FAS was estimated in South Dakota at $10,000 to $30,000 in 1982.[61] In 2002, the lifetime cost of a child in the United States with FAS was projected at $2 million. Because of these significant lifetime costs, researchers have tried to estimate the cost savings of FAS prevention. Based on a study conducted in North Dakota in 1996-97, Klug and Burd calculated the annual health care cost saving per FAS child at $2,342 based on an annual average cost of health care for children of $500.[62]

A recent Canadian study by Stade et. al. puts the total adjusted cost for a child with FASD at $14,342 a year, with the annual cost to Canada for care for all FASD children aged 1-21 years at $344,208,000.[63] To determine costs, information was collected from parents (n=148) about the health services utilized for their child with FASD. The study sample was drawn from participants of FASworld Canada, a national parent support group. Questions were asked about direct costs for medical care (hospital admissions, professional services, medication), educational services (home and special schooling), social services (respite care, foster care) and costs for the parents (parking, transportation and externalizing behaviours such as property damage). Indirect costs related to parents' loss of productivity were estimated through queries about missed workdays to care for a child with FASD. Severity of disability, age of child, and geographical setting were significant determinants of costs and were adjusted to determine the average annual total costs of care. Costs for care increased the greater the disability. The highest cost for care of a child with FASD is in early adolescence. Costs were the least in eastern Canada and the highest in western Canada. The unadjusted cost to parents was $2,454 (19% of costs) and to society (ministry of health/social services) $10,567. Costs may be an underestimate as individuals with FASD in institutional care (who may have the most severe disabilities) were not included. Costs may also have been higher had the homeless with FASD and those in the justice system been represented.

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[60] Lupton et. al., op. cit.
[61] Klug et. al., op. cit.
[62] Ibid.
[63] Stade et. al., op. cit.

2.2.1 Recommendations for determining costs of FASD in Atlantic Canada

The United States' cost estimates for FASD are older, and particularly with the difference in health care costs between the two countries, likely not relevant for use in Canada. The Canadian study by Stade et. al. should be much more representative of the costs for care here in Atlantic Canada.

- Initially, the Stade et. al. costs[64] could be applied in Atlantic Canada to estimate the costs for care of children with FASD from 1 to 21 years. Although this study did not use a random sample, the sample was heterogeneous, allowing for generalizability to the Canadian population. The study was fairly recent, and costs are broken down for the individual services. The adjusted rates for disease severity and place of residence are included.

- To arrive at a more comprehensive estimate of the lifelong costs of FASD in Atlantic Canada, a study should be conducted to determine the cost of residential/institutional and community care for individuals with FASD beyond age 21 years and justice costs for all ages.

2.2.2 Economic costs of FASD in Atlantic Canada

The FAS/FAE Tool Kit estimated the annual cost for FAS in the Atlantic Provinces at $57 million based on a lifetime cost for FAS at $1.5 million per person (estimate from the Manitoba Child and Youth Secretariat), an average lifespan of 60 years and an incidence rate of 1 per 1,000.[65] To update these estimates for the purposes of this review and synthesis of information, the Canadian costs measured by Stade et. al. for FASD were applied to current population estimates using the prevalence rate of 10 per 1,000 births.[66] [67] Table 1 presents our estimates of the annual costs for FASD in 2006 for all Atlantic Canada and the individual provinces.

[64] Ibid.
[65] Health Canada, op. cit.
[66] May et. al., op. cit.
[67] Stade et. al., op. cit.

Table 1 Estimate of average annual costs of FASD in Atlantic Canada in 2006

Costs		Atlantic Provinces	NS	NB	NL	PE
Direct costs:						
Medical (30.3%)	Neonatal (n=212)	$3,386,869 (212 infants x $15,975.80)	$1,376,635 (n=86)	$1,086,354 (n=68)	$702,935 (n=44)	$223,661 (n=14)
	Hospitalization, ER/clinic visits, health professional visits, medical devices, medications and dispensing fees, diagnostic tests	$23,354,319 (5874 children aged 0-21 x $3,975.88)	$9,398,980 (n=2364)	$7,442,847 (n=1872)	$4,985,753 (n=1254)	$1,526,738 (n=384)
Education (32.6%)	Home schooling, special schooling, and residential programs	$25,113,112 (5874 children aged 0-21 x $4,275.30)	$10,106,809	$8,003,362	$5,361,226	$1,641,715
Social Services (21.9%)	Respite care, foster care, legal aid	$16,835,060 (5874 children aged 0-21 x $2,866.03)	$6,822,575	$5,365,208	$3,594,002	$1,100,556
Out-of-Pocket (7.1%)	Transportation to visits, parking, externalizing behaviour	$5,498,710 (5874 children aged 0-21 x $936.11)	$2,212,964	$1,752,398	$1,173,882	$359,466
Total direct costs (91.9%)		**$74,188,070**	**$29,917,963**	**$23,650,169**	**$15,817,798**	**$4,852,136**
Indirect costs: Productivity Losses (8.1%)		$6,198,539 (5874 parents of children aged 0-21 with FASD x $1,055.25)	$2,494,611	$1,975,428	$1,323,284	$405,216
Total costs * for children 0-21 years with FASD		**$80,386,609 (n=5874)**	**$32,412,574**	**$25,625,597**	**$17,141,082**	**$5,257,352**
Total costs for persons with FASD aged 22-64 years**		**$80,295,107 (14,129 persons with FASD aged 22-64 years X $5,683.00)**	**$31,938,460 (n=5620)**	**$25,857,650 (n=4550)**	**$17,901,450 (n=3150)**	**$4,546,400 (n=800)**
Total annual costs of FAS for 2006***		**$160,681,716**	**$64,351,034**	**$51,483,247**	**$35,042,532**	**$9,803,752**

* As no Canadian costs for adult FAS care were found, these costs are based on the adjusted annual costs for persons aged 18-21 years estimated by Stade et. al.

** The FAS/FAE Tool Kit used an average lifespan for a person with FAS at 60 years, as study subjects were never older than 60 years, and it was speculated that those with FAS are more vulnerable to violence, suicide, and early death. We based our calculation on the Tool Kit premises and the population estimate age ranges available for 2006.

*** Provincial totals do not equal the Atlantic Canada totals due to rounding off.

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Out-of-Pocket (7.1%)	Transportation to visits, parking, externalizing behaviour	$5,498,710 (5874 children aged 0-21 x $936.11)	$2,212,964	$1,752,398	$1,173,882	$359,466
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Total costs * for children 0-21 years with FASD		**$80,386,609 (n=5874)**	**$32,412,574**	**$25,625,597**	**$17,141,082**	**$5,257,352**
Total costs for persons with FASD aged 22-64 years**		**$80,295,107 (14,129 persons with FASD aged 22-64 years X $5,683.00)**	**$31,938,460 (n=5620)**	**$25,857,650 (n=4550)**	**$17,901,450 (n=3150)**	**$4,546,400 (n=800)**
Total annual costs of FAS for 2006***		**$160,681,716**	**$64,351,034**	**$51,483,247**	**$35,042,532**	**$9,803,752**

* As no Canadian costs for adult FAS care were found, these costs are based on the adjusted annual costs for persons aged 18-21 years estimated by Stade et. al.

** The FAS FAE Tool Kit used an average lifespan for a person with FAS at 60 years, as study subjects were never older than 60 years, and it was speculated that those with FAS are more vulnerable to violence, suicide, and early death. We based our calculation on the Tool Kit premises and the population estimate age ranges available for 2006.

*** Provincial totals do not equal the Atlantic Canada totals due to rounding off.

As noted in Table 1, the health care costs for neonates in Atlantic Canada with FASD (n=212) are estimated at $3,386,869 in 2006. Health care costs for all children with FASD to age 21 (n=5874) are estimated to be $23,354,319. Education costs (including home schooling, special schooling and residential programs) for the same cohort are estimated at $25,113,112. Respite care, foster care and legal aid services cost $16,835,060. Out-of-pocket expenses for parents to cover transportation and parking costs, as well as costs incurred as a result of actions such as theft and property damage are calculated to be $5,498,710. Total direct cost to society for those aged 21 years or less with FASD in 2006 is calculated at $74,188,070. The cost for parents' loss of productivity due to the FASD is calculated at $6,198,539. Total direct and indirect costs for FASD children to age 21 years in Atlantic Canada are estimated at $80,386,609 for 2006.

According to Stade et. al., FASD-related costs are lower in eastern Canada (Newfoundland and Labrador, New Brunswick, Nova Scotia and Quebec) at $9,756 compared to the unadjusted value of $13,108.57 used for this analysis.[68] The national rate was chosen for the purpose of this analysis because the eastern Canadian figures reported by Stade et. al. included Quebec and excluded Prince Edward Island. While the results presented here may appear overestimated, parents in eastern Canada reported a lack of sufficient health and educational services, so it has been suggested the costs are lower only because the appropriate services are not available.[69]

No Canadian dollar figure for care and services for adults with FASD was found. For the purposes of this report, the Stade et. al. cost for care and services for those aged 18 to 21 years was applied to the estimated proportion of adults with FASD, aged 22 to 64 years, in Atlantic Canada (n=14,129) yielding an additional annual cost of $80,295,107. The total estimate for all FASD care and services in Atlantic Canada for 2006 is $160,681,716. It should be noted that the costs for adults can only be considered a rough estimate. A Canadian study similar to that conducted by Stade et. al. focussing on adults with FASD would illuminate the true costs of care and services for this population. Any adult-focussed study should also investigate judicial/offender costs and expenses for long-term residential and/or community care (the Correctional Service Canada study on the prevalence of FASD in the offender population will provide useful information toward an understanding of costs associated with this population). There is also scant information about the lifespan of an individual with FASD, which would also contribute to understanding and determining the true costs of FASD in Atlantic Canada.

Lifetime costs for an individual with FASD are estimated at $535,624.77, based on a life expectancy of 64 years using the costs listed in Table 1. This is lower than the figure cited in the FAS/FAE Tool Kit of $1.5 million and the most recently updated United States costs of $2 million over a lifetime. However, the costs reported here represent an average of costs for all persons affected by an FASD (mild through to severe), rather than the costs for a child with FAS (the most severe form) as calculated in those reports.

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[68] Ibid.

[69] Ibid.

3. FACTORS CONTRIBUTING TO FASD IN ATLANTIC CANADA

To begin to situate an issue such as FASD in the Atlantic Region, it is important to understand the attitudes, knowledge and behaviours that contribute to the problem. Understanding knowledge and attitudes towards FASD is important since it must be assumed that poor public and professional understanding may contribute to the problem. It is also important to explore what is known about knowledge, attitudes and behaviours concerning alcohol consumption in the region, particularly by pregnant women, women of child-bearing age and their partners. Public opinion concerning alcohol policy measures that have the potential of increasing or decreasing alcohol consumption needs to be considered. Relatively little relevant documentation was found on these topics (that is, documentation published in Atlantic Canada or national documentation that included attention to Atlantic Canada).[70] This section synthesizes that which was found. Taking a broader view, it has been suggested that the social determinants of health may have a bearing on FASD prevalence; there is little literature from within the region or otherwise that provides data on this question, but it will nevertheless be briefly explored.

3.1 KNOWLEDGE AND ATTITUDES CONCERNING FASD

3.1.1 Public knowledge and attitudes

The Environics report, *Alcohol Use during Pregnancy and Awareness of Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder*, a national study commissioned by the Public Health Agency of Canada, provides the only relevant information found on public knowledge and attitudes surrounding FASD.[71] This survey of women aged 18 to 40 years and their partners within the same age range was a replication of a study conducted in 2002 and 1999 and was thus able to report on changes. Although Atlantic Canadians were surveyed, the report presents very little information on how respondents in this region differed from their counterparts, so unless otherwise noted, the national picture is presented.

Overall, FASD-related knowledge and awareness among women and men in this age range have steadily increased since the first survey. The report indicated that there is good surface-level understanding of the nature of FAS across the country. For example, virtually everyone surveyed (98%) was aware that alcohol use during pregnancy is harmful and that the likelihood and extent of harm increases with amount consumed. In a similar vein, most people were aware of the terms FAS/FAE; however, there was less clarity on the nature and severity of the disorder. A significant minority thought the effects of alcohol on the fetus were unclear, which is not the case. Atlantic women were less likely than their counterparts across Canada to understand FAE effects.

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[70] Excluded were reports from provinces outside the region.

[71] Environics, *Alcohol Use during Pregnancy and Awareness of Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder. Results of a National Survey*, Public Health Agency of Canada, Ottawa, 2006.

The report, *What We Have Learned: Key Canadian FASD Awareness Campaigns*, briefly discusses the impact of stigma in impeding progress on this issue.[72] Stigma surrounding any issue can serve as a barrier to social inclusion and to accessing services. Although there is no Canadian information to refer to, it is known that society can stigmatize individuals with FASD. Individuals with FASD may be harshly judged by those who do not understand that their actions are a consequence of brain damage, rather than wilful misconduct. Widespread misunderstanding of the long-term consequences of FASD may impede the development of appropriate services for those affected. It is important to be clear that early diagnosis followed by appropriate care can reduce the burden on families and on the service and legal systems.[73]

3.1.2 Professional knowledge and attitudes

Information on the knowledge and attitudes of health care professionals across Canada was reported in Clarke's study, *Knowledge and Attitudes of Health Professionals about Fetal Alcohol Syndrome: Results of a National Survey*, which randomly sampled paediatricians, psychiatrists, obstetricians and gynaecologists, midwives and family physicians.[74]

Professional understanding parallels that of the general public in several ways. According to the study, general understanding of the disorder was high among health care professionals, but 25% felt that the effects of alcohol on the fetus are unclear. Most practitioners saw diagnosis of FAS/FAE as being within their scope of practice, and a high percentage believed that diagnosis leads to improved outcomes. However, a diagnostic understanding of FAS, and more so, FAE, was not strong. For example, only a small proportion (14%) correctly identified that FAE is not a less severe form of FAS, and the long-term outcomes associated with FAS and FAE were not well understood. Health care professionals across all regions and all professional groups identified lack of specific training as the greatest barrier preventing them from becoming more involved in diagnostic activity. Respondents in the Atlantic Region were most likely to say that lack of training is problematic.

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[72] W. Burgoyne, *What We Have Learned: Key Canadian FASD Awareness Campaigns*, Public Health Agency of Canada, Ottawa, 2006.

[73] A.P. Streissguth, H.M. Barr, J. Kogan, and F.L. Bookstein, *Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)*, University of Washington School of Medicine, Seattle, 1996.

[74] M. Clarke, *Knowledge and Attitudes of Health Professionals about Fetal Alcohol Syndrome: Results of a national survey*, Public Health Agency of Canada, Ottawa, no date.

3.2 KNOWLEDGE AND ATTITUDES CONCERNING ALCOHOL USE BY WOMEN OF CHILD-BEARING AGE

3.2.1 Public knowledge and attitudes

According to the 2006 Environics public awareness survey, knowledge of the importance of cutting back or stopping alcohol use as a very important way to increase chances of a healthy outcome for a baby is widespread; most women indicate that they would stop or cut back drinking once aware they are pregnant. Many Aboriginal women are knowledgeable about the risks of alcohol to the fetus. In the 2002 Environics survey, 53% of Aboriginal women indicated that decreasing or stopping alcohol use was important for delivering a healthy baby, about the same percentage as non-Aboriginal respondents.[75] Men as well as women who drink more per week and women in lower socio-economic groups and in rural areas are somewhat less knowledgeable about the risks of alcohol use during pregnancy. Atlantic women were less likely than Canadian women generally to perceive four or five drinks on weekends as being not at all safe. While declining since 2002 and 1999, confusion still exists around the risks to the fetus from consuming "moderate" amounts of alcohol and what constitutes a small amount.

Focus group work conducted for the Public Health Agency of Canada in 2005 among women of child-bearing age found the same confusion – that while there was general awareness that drinking large amounts of alcohol regularly was harmful, there remained a belief that occasional drinking would be safe. There was a wide variation in what women of all ages understand to be low-risk, moderate, heavy and binge drinking. For example, descriptions of binge drinking included no longer being in control, becoming sick, passing out, drinking eight to 10 drinks in one evening or drinking heavily for an extended period of time such as a weekend.[76]

The report, *What We Have Learned: Key Canadian FASD Awareness Campaigns*, noted the misconceptions and myths around women and alcohol use, which are compounded when alcohol use occurs within the context of pregnancy and motherhood. These misunderstandings can translate into discriminatory practices and attitudes when dealing with women around substance use issues. Pregnant women who use alcohol may find it difficult to access the services they need due to judgmental attitudes of service providers, feelings of shame, depression, low self-esteem and fear of losing their children. Family and friends may also discourage a pregnant woman from talking about her alcohol use, due to concerns about reprisal.

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[75] Environics. *Alcohol Use during Pregnancy and Awareness of Fetal Alcohol Syndrome*, Public Health Agency of Canada, Ottawa, 2002.

[76] M. Johnston, *Alcohol Consumption by Women of Child-Bearing Age: A Modifiable Risk Factor*, Public Health Agency of Canada, Ottawa, 2006, www.phac-aspc.gc.ca/ccasn-rcsac/ct2006/consumption-consommation

3.2.2 Professional knowledge, attitudes, and practices

The national survey of health professionals found that there was good common understanding of how "moderate" drinking for non-pregnant women should be defined (i.e., two or fewer drinks per occasion/three or fewer drinking occasions per week), and most agreed with the practice of advising patients in the general population to drink in moderation.[77]

Most practitioners reported asking pregnant patients about their alcohol use, but fewer use a standardized screening tool (e.g., T-ACE, TWEAK). (The routine use of a standard screen for alcohol use among all prenatal women is considered a best practice because practitioners are known to miss many vulnerable women if they screen only on suspicion.)[78] Practitioners in the Atlantic Region were less likely than their counterparts in other parts of Canada to routinely use a standard screening tool.

According to the survey, the majority of Canadian health care professionals have been appropriately counselling women who are known to drink that it is best not to consume any alcohol during pregnancy, and Atlantic practitioners were somewhat more likely to report doing so.

However, practitioners tended to feel less capable in caring for alcohol-dependent pregnant women or birth mothers, and Atlantic Canadians were particularly likely to report this. Only slightly more than one-half were referring patients for treatment who self-reported as binge or heavy drinkers. Those who reported feeling prepared to deal with these issues differed from their colleagues who reported feeling unprepared. Those who were prepared were more likely to:

- be over the age of 40 years
- hold university appointments
- gain knowledge regarding FAS from patients, colleagues, continuing medical education or medical journals
- routinely obtain detailed family and personal histories regarding abuse and addictions
- include in their routine primary care of women of child-bearing age discussion of folic acid; the risks of smoking, alcohol, and drug use during pregnancy as well as nutrition and partner-use of drugs and alcohol.

Overall, it appears that Atlantic physicians and their counterparts across the country have improved their knowledge and practice concerning alcohol use and pregnancy. Nevertheless, there is a clear need for more professional development in this area to entrench best clinical practices. For example, the fact that almost 70% of physicians said they always discuss the adverse effects of alcohol with pregnant women who indicate they use alcohol moderately means that 30% do not.

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[77] Clarke, op. cit.

[78] Roberts et. al., op. cit.

Even among those who reported feeling prepared to deal with alcohol use problems, less than 20% of physicians routinely screened for sexual or emotional abuse, even though these are two important risk factors related to drinking during pregnancy.

Moreover, there is a small minority of practitioners whose needs are stronger still. Approximately 10% of practitioners across Canada and in the Atlantic Region reported advising consumption of beer and wine in moderation during pregnancy. Given that this message runs counter to current practice guidelines, the Clarke report further investigated this population. It was noted that this population of practitioners differed significantly from their colleagues who advise "no alcohol" in several ways. Those advising moderate drinking were:

- less likely to get information from medical journals and books
- more likely to report there is not enough solid information available about alcohol use
- more likely to report that their clients are not interested in discussing alcohol use
- more likely to report that information about alcohol use is not available in a form that was useful to their clients.

3.2.3 Public opinion concerning alcohol policy measures

A significant weight of evidence shows that public health-oriented alcohol policy measures (e.g., linking taxes to alcohol strength and cost of living index, limiting density of outlets and hours of sale, raising the drinking age) are among the most effective ways to reduce harms associated with alcohol.[79] Nevertheless, there are major factors influencing policy away from a public health orientation (e.g., the interests of multi-national alcohol producers and the local hospitality industry, economic globalization). Certainly, public opinion concerning the control and sale of alcoholic beverages influences the likelihood that any measure will be considered.

Using data collected by the Canadian Centre for Substance Abuse 2004 Canadian Addiction Survey, estimates of public support in Atlantic Canada for several policy measures were calculated.[80] When asked specifically whether taxes on alcohol should be increased, decreased, or stay the same, most respondents (62.4%) thought taxes should stay the same, 25.2% thought they should be increased and 12.4% decreased. It appears that responses were based in part at least on an erroneous understanding of the preventative effect of this measure. A clear majority (71.7%) did not feel raising taxes to be effective in this regard.

When asked whether the legal drinking age should be raised, lowered or stay the same, most respondents (60.8%) thought the legal drinking age in Atlantic Canada should stay the same, with 35% advocating for the legal drinking age to be raised and 4.2% for it to be lowered.

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[79] Babor et. al., op. cit.

[80] L. Graham, *Canadian Addiction Survey Analyses*, unpublished results.

Of some relevance to this issue, the majority of Atlantic Canadian respondents (75.9%) thought efforts to prevent intoxicated customers from being served should be increased, while 44.2% thought the government should prohibit alcohol advertising on television.

3.3 ALCOHOL CONSUMPTION PATTERNS ASSOCIATED WITH FASD[81]

While FASD are caused by prenatal exposure to alcohol, effects vary widely, and it is known that other factors, such as maternal health, nutrition, genetic susceptibility and use of other psychoactive substances influence outcomes as well.[82] In turn, alcohol use can be influenced by social factors and the broader determinants of health, including social norms and expectations, poverty and violence.[83] Pregnancy serves as a strong motivator to reduce or stop drinking.[84] Pregnant women who continue to drink alcohol are usually alcohol-dependent women who often make other efforts to improve their health, such as paying attention to diet, taking prenatal vitamins and cutting back on smoking.[85]

3.3.1 Adolescent girls

Student survey reports from each of the Atlantic Provinces underscore the fact that adolescents have a high rate of alcohol use.[86] [87] [88] [89] Rates of use are fairly even between males and females overall, and they increase dramatically from middle school through the high school years, as can be seen from the table presenting figures from the provinces reporting this information:

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[81] In reviewing the following data, note that alcohol consumption levels, particularly maternal consumption, are often significantly underestimated. Data on rates of drinking during pregnancy are commonly based on self-reporting and are therefore often unreliable as a result of poor estimation, poor recollection, and the social stigma associated with heavy drinking during pregnancy. This is compounded by variation in the alcoholic concentration of different types of drink, variation in serving size (e.g., difference sizes of wine glass), and the difference between the standard measures used in bars and restaurants and the amounts poured off premises.

[82] Roberts et. al., op. cit.

[83] Ibid.

[84] N. Poole, T. Horne, L. Greaves, D.M. Chovanec, and M. Watkins, *Windows of Opportunity: A statistical profile of substance use among women in their childbearing years in Alberta*, Alberta Alcohol and Drug Abuse Commission, Edmonton, 2004.

[85] Ibid.

[86] C. Poulin and B. Wilbur, *Nova Scotia Student Drug Use Survey 2002: Technical Report*, Nova Scotia Department of Health, Addiction Services, and Dalhousie University, Halifax, 2002.

[87] L. Van Til and C. Poulin, *2002 Prince Edward Island Student Drug Use Survey: Technical Report*, Prince Edward Island Department of Health and Social Services, Prince Edward Island Department of Education, and Dalhousie University, Charlottetown, 2002.

[88] J. Liu, B. Jones, C. Grobe, C. Balram et. al., *New Brunswick Student Drug Use Survey 2002: Highlights Report*, New Brunswick Department of Health and Wellness, Fredericton, 2002.

[89] C. Poulin, D.S. Martin, and M. Murray, *Newfoundland and Labrador Student Drug Use Survey 2003: Summary Report*, Newfoundland and Labrador Department of Health and Community Services, St. John's, 2005.

Table 2 Percentage of adolescents having used alcohol in the past year by gender overall, and by grade, 2002

	Male	Female	7	9	10	12
PE	49	49	10	39	63	81
NB	51	55	11	50	70	85
NS	52	53	16	52	65	81

Of greater concern are the rates of hazardous use, which are high relative to other age groups. For example, Nova Scotia and Newfoundland and Labrador presented rates of drunkenness in the past year and past month respectively: 41% of Nova Scotia Grade 10 and 12 girls reported having gotten drunk in the past year, while 50% of Newfoundland and Labrador Grade 10 and 12 girls reported having gotten drunk in the past month (the same rates as boys in both cases).

Alcohol consumption is part of a pattern of adolescent risk-taking behaviours that tend to cluster. For example, young women who are more sexually active are more likely to have been drunk compared with sexually non-active young women. With a sample of Atlantic Canadian Grade 9, 10 and 12 students, Poulin and Graham[90] found that about 37% of males and 39% of females reported having engaged in sexual intercourse in the previous 12 months. Of those, 68% of males and 61.5% of females reported having engaged in unplanned sexual intercourse, 40.9% of males and 32.1% of females reported having more than one sexual partner and 49.9% of males and 64.1% of females reported inconsistent condom use. These patterns are associated with unplanned pregnancy and sexually transmitted infections, and they may lead to fetal alcohol exposure.

There is also evidence that adolescents do not recognize their pregnancies as early as other women.[91] This can be a problem, as drinking in the early stages of pregnancy, before a woman realizes she is pregnant, may have life-long consequences for the resulting child.

Rates of hazardous alcohol use and other high risk behaviours are not well established for female youth who are not enrolled in school or are living on the street but are assumed to be higher still.[92]

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[90] C. Poulin and L. Graham, "The association between substance abuse, unplanned sexual behaviours among adolescent students," *Addiction*, 2001, 96(4), pp. 607-621.

[91] C. Dell and G. Roberts, *Alcohol use and pregnancy: An important Canadian public health and social issue*, Health Canada, 2006.

[92] Ibid.

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[92] Ibid.

3.3.2 College and University Women

High rates of use and hazardous use found in high school continue into the postsecondary years. The 2004 Canadian Campus Survey, which sampled students from 49 universities, found alcohol use to be very frequent and particularly so among students at Atlantic universities. Table 3 summarizes the survey's findings.

Table 3. Alcohol use among Canadian university students, 2004

Indicator	Total	Male	Female	Atlantic
% Past year use	85.7	84.0	87.1	90.0
% Past month use	77.1	76.5	77.7	85.2
% Heavy/frequent	16.1	20.6	12.5	23.2
% Hazardous/harmful drinking (AUDIT 8+)	32	37.6	27.5	40.5

There was little difference between the genders in terms of the prevalence of past year alcohol use; males were more likely to engage in hazardous use, but female rates were nevertheless high.

The average age of the undergraduate women was 22 years, and 12.8% reported unplanned sexual activity due to alcohol.

3.3.3 Women in Atlantic Canada

Data collected in the 2004 Canadian Addiction Survey were used to investigate the drinking habits of Atlantic Canadian women of child-bearing age, 15 to 44 years. Most child-bearing-aged women (81.2%) in Atlantic Canada reported drinking in the year prior to the survey. Heavy drinking (four or more drinks at a sitting) at least once a month was reported by 23.7% of women of child-bearing age, and 4.8% reported heavy drinking weekly. A number of female survey participants of child-bearing age in Atlantic Canada (13.6%) were identified as high-risk drinkers, scoring 8 or more on the Alcohol Use Disorders Identification Test (AUDIT).

In the 2000/01 Canadian Community Health Survey (CCHS), 62.8% of females 12 years and older in Atlantic Canada consumed five or more drinks on one occasion in the year prior to the survey. 23.1% consumed this amount on one occasion less than 12 times in the

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[93] E.M. Adlaf, A. Demers, and L. Gliksman (Eds.), *Canadian Campus Survey 2004*, Centre for Addiction and Mental Health, Toronto, 2005.

[94] L. Graham, op. cit.

[95] The AUDIT is a tool used to identify hazardous consumption, harmful alcohol use patterns, and alcohol dependence. A score of 8 or more signifies a pattern of high-risk alcohol use.

prior year, and 14.1% consumed this amount 12 or more times in the year prior to the survey.[96 97]

3.3.4 Pregnant Women

Findings from recent Canadian surveys indicate that approximately 14% of women reported alcohol consumption during pregnancy.[98 99]Most women reported infrequent use during their pregnancy, with 75.4% using alcohol less than once a month and 9.7% once a month. However, 6.5% of pregnant women reported using alcohol two to three times a month, 5.3% reported weekly use and 1.3% consumed alcohol daily.[100] Women are naturally protective of their unborn child. If a woman drinks alcohol during pregnancy, there are a number of possible explanations, including:

- she does not know she is pregnant
- she does not know how harmful prenatal exposure to alcohol can be
- she uses alcohol to self-medicate for an undiagnosed mental health concern
- she consumes alcohol because it is a norm or expectation in her social network
- she drinks alcohol because it helps her cope with difficult life issues such as stress, poverty or violence
- she is dependent on alcohol.[101]

3.3.5 Aboriginal women

Compared to the population at large, there are little data on the use of alcohol by Canadian Aboriginal women. On the other hand, most of the studies of FASD rates focus on Aboriginal women in communities where alcohol use problems and dependency are known to be high. There is little knowledge of the prevalence of FASD in non-Aboriginal communities. These gaps in knowledge call for caution in ascribing high rates of FAS/E in the general Aboriginal population on the basis of rates found in selected Aboriginal communities. It also means the rate of FASD in other populations is unknown, making it difficult to determine whether or not Aboriginal women are, in fact, at greater risk than other groups.[102]

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[96] R. A. Cormier, C.A. Dell, and N. Poole, *Women's Health Surveillance Report. A Multi-Dimensional Look at the Health of Canadian Women*, Canadian Institute for Health Information, Ottawa, 2003.

[97] The Atlantic Canadian values reported here are averages calculated from the 2000-01 CCHS mean provincial rates. Available at www.statcan.ca/english/freepub/82-221-XIE/00502/tables/pdf/2156.pdf

[98] C. McCourt, D. Paquette, L. Pelletier, and F. Reyes, *Report on Maternal and Child Health in Canada. Making Every Mother and Child Count*, Public Health Agency of Canada, Ottawa, 2005.

[99] Dell et. al., op. cit.

[100] Ibid.

[101] Burgoyne, op. cit.

[102] C. Tait, *Fetal Alcohol Syndrome and Fetal Alcohol Effects: the 'Making' of a Canadian Aboriginal Health and Social Problem*, unpublished dissertation manuscript, McGill University, Montreal, 2004.

3.4 DETERMINANTS OF HEALTH AND FASD

While knowledge, attitudes and behaviours related to alcohol consumption and FASD are important factors that may increase the likelihood of problems (i.e., risk) or of well-being (protective), it is important to recognize that other, more fundamental factors are also at play. It is now commonly accepted that a number of "determinants" have great influence over the health of a population. The factors that are generally understood to influence population health are income and social status, social support networks, education, employment/working conditions, social environments, physical environments, personal health practices and coping skills, healthy child development, biology and genetic endowment, health services, gender and culture.[103]

This relationship appears to hold for FASD. As Boland notes in her paper for the Burin Peninsula Brighter Futures agency in Newfoundland and Labrador, the lives of women at risk of having an FASD child are complex and need to be understood from a broad perspective.[104] It has been hypothesized that low socio-economic status (often used as a proxy for the range of determinants) is associated with FASD.[105] [106] Because our knowledge of the prevalence of FASD in the general population is incomplete, understanding of the relationship between FASD and the determinants of health remains somewhat tentative. Nevertheless, it warrants brief exploration in the context of this report.

North American surveys generally report that the likelihood of drinking during pregnancy increases with income. For example, an analysis of 2000-01 CCHS data for Alberta shows clear income-based differences among women who reported drinking alcohol during their last pregnancy: 40.5% of women with an income over $80,000 reported drinking, with this rate steadily declining to 9.9% of women with an income of $29,999 and under. However, when they did drink, lower-income pregnant women were more likely to binge drink (i.e., drink five or more drinks per occasion). To illustrate, 9.2% of women with incomes less than $10,000 reported binge drinking at least once a month, while 4-5% of women in income groups over $20,000 did so. Because peak blood level on any occasion is a critical factor for determining the extent of fetal damage, measures of binge drinking are generally viewed as particularly relevant to FASD and its prevention.

The socio-economic status of Atlantic Canadians is low in relation to Canadians in other regions, and within the region, large differences exist across ethnic groups and socio-economic classes.[107] Also, a greater proportion of the population in Atlantic Canada lives in rural settings; rural living may influence health in different ways, including limiting access to services. The mechanisms by which socio-economic and other factors influence alcohol consumption need to be better understood, but there can be little doubt that a small

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[103] Public Health Agency of Canada, *What determines health?* www.phac-aspc.gc.ca/ph-sp/phdd/determinants/determinants.html

[104] B. Boland, *Gender Analysis of FASD: A Discussion Paper*, Burin Peninsula Brighter Futures Inc., 2006.

[105] Abel, op. cit.

[106] E.L. Abel and J. H. Hannigan, "Maternal risk factors in Fetal Alcohol Syndrome: Provocative and permissive influences," *Neurotoxicology and Teratology*, 1995, 17(4) pp. 445-462.

[107] N.R. Sharif, A.A. Dar, and C. Amaratunga, *Ethnicity, Income and Access to Health Care in the Atlantic Region: A Synthesis of the Literature*, Maritime Centre of Excellence in Women's Health, Halifax, 2000.

proportion of women of child-bearing age in the region find themselves in socio-economic circumstances that are associated with hazardous levels of alcohol consumption during pregnancy.

3.5 TOWARDS A DEMOGRAPHIC PROFILE OF FASD IN ATLANTIC CANADA

The development of a demographic profile of women at risk of having an alcohol-exposed child needs to be approached with caution. While the population of mothers at risk of having a child with FAS is reasonably well understood, the characteristics of mothers at risk who have children with other alcohol-related effects are less clear. Many of the studies that explore the characteristics of at-risk women do not employ samples that are representative of the general population.[108] Various studies find that about 15% of women drink while pregnant; much of this consumption is light, and much is early in the pregnancy before the pregnancy is discovered.[109] It appears from the above discussion that women who report drinking hazardously at least early in pregnancy are more likely to have a lower income.[110]

Women aged 25 or older with several children and who continue to drink hazardously (i.e., higher volumes or binge use) during their pregnancy are most likely to have a child with FAS.[111] These women are likely to be alcohol-dependent and as such, are often multiple substance users (heavy cigarette use is closely linked), have partners with substance use problems and often have a history of experiencing family violence, sexual abuse, early onset of drinking, and mental illness, suggesting a pattern of self-medication to cope with these issues.[112] Some women who bear alcohol-exposed children themselves have alcohol-related brain dysfunction, indicating a multi-generational pattern of prenatal alcohol exposure.[113]

As this report has noted, a significant minority of adolescent and young adult women in the region have a lifestyle that includes binge drinking, and it is possible that this may occur before a pregnancy is recognized. While this clearly places a fetus at risk, maternal age appears to be a factor: infants born to older (30+) women who drink heavily are more likely to be functionally impaired than infants born to younger women who report similar patterns of alcohol consumption. The mechanisms underlying this phenomenon are unknown and need to be better understood.[114]

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[108] H.A. Flynn, S.M. Marcus, K.L. Barry, and F.C. Blow, "Rates and correlates of alcohol use among pregnant women in obstetrics clinics," *Alcoholism: Clinical and Experimental Research*, 2003, 27(1), pp. 81-87.

[109] Dell et. al., op. cit.

[110] It is not known but it is possible that women of higher income under-report their alcohol consumption to a greater extent than women of lower income.

[111] Abel et. al., "Maternal risk factors in Fetal Alcohol Syndrome: Provocative and permissive influences," op. cit.

[112] Roberts et. al., op. cit.

[113] Ibid.

[114] Ibid.

Less severe developmental abnormalities may occur among the infants of mothers who consume lower levels of alcohol. This suggests that a much broader range of women about which less is known may expose their children to alcohol-related damage; however, more research is needed to clarify the drinking patterns associated with less severe problems.[115]

Alcohol is a teratogen, and fetal exposure can result in neuro-developmental damage that adversely affects a person's life at every stage. Infants with an FASD have complex medical, psychological and social needs. While the physical health of children prenatally exposed to alcohol can improve through later childhood, their behavioural problems often become accentuated in school and the wider community through these years. In Canada, many alcohol-exposed infants are placed in foster or adoptive care, and lack of stability is known to aggravate problems for affected children.

Many of the psychosocial problems emerging in childhood become more pronounced among adolescents exposed to alcohol *in utero*. Early gains may not be maintained, and it is often during this period that serious problems are encountered at home and at school. Adolescents with an FASD tend to have high rates of secondary disabilities, mental illness, substance abuse, trouble with the law, school failure, problems with sexual expression and homelessness. Most persons with FAS are not able to live totally independent lives at any point. Central nervous system damage results in a patchwork of competencies and limitations that vary among individuals. Typically, however, the adult with FAS continues to have problems with impulsivity, attention, poor judgment, recognizing and setting boundaries, social relationships, decision-making and higher-order skills such as time and money management.

A diagnosis before age 6 reduces the likelihood of secondary disabilities and has been shown to result in lower rates of disrupted school experiences, inappropriate sexual behaviour, trouble with the law, substance abuse and institutionalized care.[116] The picture that emerges is of a population that has high needs for medical, educational, psycho-social, employment and accommodation support. The more tailored these supports are to the lives and circumstances of children and adults with an FASD, the better the outcomes for these children (i.e., the less likely that various remedial and custodial services will be required). However, there are indications that the Atlantic Region has fewer services tailored for children with an FASD, so the proportion of these children who are able to avoid its many secondary disabilities may be relatively low.[117]

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[115] Some of the studies on which these conclusions are based identify "moderate" drinking on the basis of weekly average, which may hide high "per-occasion" drinking.

[116] Roberts et. al., op. cit.

[117] Stade et. al., op. cit.

4. POLICY AND RESEARCH RESPONSE TO FASD IN ATLANTIC CANADA[118]

4.1 FASD-RELATED POLICIES

This section on relevant policy is organized between federal and provincial activity and between alcohol-related activity and FASD-related activity. Because the provinces and territories (and to some extent, municipalities) have responsibility for the provision of direct services, the federal government's opportunity for policy leadership on this issue is, for the most part, limited to policy advice and advice on strategic direction.

No alcohol-related or FASD-related policy was found for the provinces of New Brunswick or Prince Edward Island, although the government of New Brunswick, in partnership with the Beauséjour Regional Health Authority and Elsipogtog First Nation, is currently working on the creation of a provincial strategy to address prevention, diagnosis and intervention related to FASD in the province.

4.1.1 Federal alcohol-related policy or strategic activity

The National Framework for Action to Reduce the Harms Associated with Alcohol and Other Drugs and Substances, co-led by Health Canada and Canadian Centre on Substance Abuse, included the priority, "Reducing Alcohol-related Harms." This priority was operationalized by the National Alcohol Strategy Working Group which was composed of a wide range of stakeholders including two from Atlantic Canada. The group recently reached general consensus on a comprehensive strategy and identified a total of 41 recommendations in the report, *Reducing Alcohol-Related Harm in Canada: Toward a Culture of Moderation. Recommendations for a National Alcohol Strategy*.[119] While successful implementation of these recommendations could well have an impact on the prevalence of FASD, the group recognized that the issues around FASD were too complex to deal with comprehensively and as such, expressed openness to identifying ways to support the work of the national FASD initiative.

In 2000, Status of Women Canada published the report, *Substance use and pregnancy: Conceiving women in the policy-making process*.[120] Spurred in part by the controversy around the "Ms. G" case, the report examined policy in Canada dealing with the issue of substance use during pregnancy and argued for a less polarizing and punitive approach to addressing the problems. The report called for policy integration between those advocating for affected children and those advocating on behalf of women with substance use issues.

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[118] This section drew from a number of sources including stakeholder input. It is possible that it does not capture all of the relevant policy activity due to the limited time during which the search occurred and due to various interpretations of what constitutes 'policy' on the part of stakeholders.

[119] Alberta Alcohol and Drug Abuse Commission, Canadian Centre on Substance Abuse, and Health Canada, *Reducing Alcohol-Related Harm in Canada: Toward a Culture of Moderation. Recommendations for a National Alcohol Strategy*, Canadian Centre on Substance Abuse, 2007.

[120] D. Rutman, M. Callahan, A. Lundquist, S. Jackson, and B. Field, *Substance use and pregnancy: Conceiving women in the policy-making process*, Status of Women Canada, Ottawa, 2000.

The report further called for policy approaches that recognize and address the complexities of the lives of many women who are pregnant and using substances. Based on broad consultation, it called for policy shifts in the following directions:

- from a moralizing medical model to a harm reduction/health promotion philosophy
- from a child welfare mandate as protection-focussed to one that emphasizes supporting families
- from viewing child apprehension as the failure on the mother's part to failure of the system/community to provide what is needed.

4.1.2 Federal FASD-related policy or strategic activity

Over the years, the federal government has, through the lead department, Health Canada/Public Health Agency of Canada, commissioned a number of initiatives that provide policy (as well as practice) advice on FASD-related topics – for example, the initiative to produce Canadian guidelines for diagnosing FASD,[121] and the reports, *Best practices: fetal alcohol syndrome/fetal alcohol effects and the effects of other substance abuse during pregnancy*[122] and *Alcohol use and pregnancy: An important Canadian public health and social issue.*[123] Two programs funded by Health Canada (now the Public Health Agency of Canada), the Community Action Program for Children (CAPC) and the Canadian Prenatal Nutrition Program (CPNP), commissioned a report, *Enhancing Fetal Alcohol Syndrome (FAS)-related Intervention at the Prenatal and Early Childhood Stages in Canada*, which provided recommendations with FAS-related policy implications for CAPC, CPNP and other community-based agencies.[124]

The Public Health Agency of Canada has also implemented a national strategic initiative as a component of the federal government's early childhood development initiative. The national FASD initiative itself is an extension of the CPNP. Within this national initiative are two concurrent strategies directed towards FASD: the pan-Canadian FASD initiative and the First Nations and Inuit FASD program.

The pan-Canadian initiative is anchored by the document, *Fetal Alcohol Spectrum Disorder (FASD): A framework for action.*[125] Released in 2003, the framework aims to prevent FASD, build a system of supports and resources and meet the needs of individuals with FASD and their families, viewing the person with FASD at the centre of these efforts. Five goals are identified for achieving this aim:

1. increase public and professional awareness and understanding of FASD and the impact of alcohol use during pregnancy
2. develop and increase capacity

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[121] Chudley et. al., op. cit.

[122] Roberts et. al., op. cit.

[123] Dell et. al., op. cit.

[124] Margaret Leslie and Gary Roberts, *Enhancing Fetal Alcohol Syndrome (FAS)-related Intervention at the Prenatal and Early Childhood Stages in Canada*, Canadian Centre on Substance Abuse, 2001.

[125] Public Health Agency of Canada, *Fetal alcohol spectrum disorder (FASD): a framework for action*, op. cit.

3. create effective national screening, diagnostic and data-reporting tools and approaches
4. expand the knowledge base and facilitate information exchange
5. increase commitment and support for action on FASD.

According to its guiding principles, the framework is to be inclusive; guided by understanding, compassion and respect; culturally appropriate; evidence-based; and sustainable and comprehensive. The principles along with the rest of the framework would serve as a sound basis for other strategies.

A March 2005 national thematic workshop on FASD was co-hosted by the Public Health Agency of Canada and the Canadian Centre on Substance Abuse to:

- identify and prioritize issues of national significance in FASD as they relate to the development of the alcohol portion of the National Framework for Action to Reduce the Harms Associated with Alcohol and Other Drugs and Substances
- identify areas for linking the National Framework on FASD with the National Framework for Action to Reduce the Harms Associated with Alcohol and Other Drugs and Substances.

The First Nations and Inuit FASD program is guided by a framework developed in 1997 and outlined in the report, *It Takes a Community*.[126] The goals of this framework and the First Nations and Inuit FASD program in general are two-fold: the prevention of FASD births and providing supports and increasing the quality of life for individuals affected by FASD. These goals are supported by four objectives: raising awareness, reaching those at risk, working with those affected and creating linkages.

Under this program, the federal government provides funding coordination, communication and other supports, while the communities are responsible for delivery and service provision.

4.1.3 Provincial FASD-related policy or strategy

At the provincial level in the Atlantic Region, there is very limited policy-level acknowledgment of FASD.[127] The government of Newfoundland and Labrador published *Education and support standards for pregnancy, birth and early parenting* which cites alcohol-involved women as being at risk, includes alcohol use/reduction as important indicators for policy program success and identifies linking with coalitions or networks addressing FASD among other issues within its standards.[128] Smith and Rosales in their paper note that, beginning in 1998, FAS/FAE became a qualification for Categorical Special Education in Newfoundland and Labrador.[129] Under policy direction from the

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[126] FAS/FAE Technical Working Group, *It Takes a Community: Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative*, Health Canada, First Nations and Inuit Health Branch, 1997.

[127] Clinesmith, op. cit.

[128] Government of Newfoundland and Labrador, *Education and support standards for pregnancy, birth and early parenting*, 2005.

[129] Smith et. al., op. cit.

Department of Health and Community Services, the Intervention Services programs delivered by the independent Health Boards in Newfoundland and Labrador currently have no FASD-specific policies or procedures – preschoolers with FASD may be seen for service only if they show significant developmental delay or are at risk. A FASD diagnosis alone does not constitute risk, and while eligibility for service is determined on an individual basis, these children fall under a generic early intervention service policy. Individuals who are of school age and above meet criteria for service only if they have significant cognitive delay and maladaptive behaviours. A diagnosis of an FASD is not sufficient for service provision.[130]

4.1.4 Provincial alcohol-related policy or strategy

The province of Newfoundland and Labrador issued a policy paper, *Working together for mental health: A provincial policy framework for mental health and addiction services for Newfoundland and Labrador*, which mentions FASD in the context of a number of health issues particularly prevalent among Aboriginal people.[131]

In the Nova Scotia Provincial Addiction Services Standards, there is a specific statement relative to intake: "100% who self-identify as pregnant will be offered appropriate services within three working days." In 2004, there was an amendment to the Nova Scotia Liquor Control Act Regulations concerning alcohol and pregnancy (96A): "Within six months of the coming into force of this Section, the Governor in Council shall make regulations requiring the Corporation to post signs and otherwise publicize, in such manner as the regulations provide, the potential negative effects of the consumption of alcohol during pregnancy."[132]

The Nova Scotia Department of Health Promotion and Protection, Addiction Services, is currently in the process of drafting a provincial alcohol strategy. This office will have responsibility for the overall leadership, implementation, management and evaluation of the strategy and for ensuring ongoing coordination and collaboration among government, District Health Authorities and non-government organizations. Through reference to the scientific literature and broad consultation with stakeholders, five key directions have been identified:

1. community capacity and partnership building
2. communication and social marketing
3. strengthening prevention, early intervention and treatment
4. healthy public policy
5. research and evaluation.

It is intended that each District Health Authority or Shared Service Area (combined District Health Authorities) will develop an alcohol strategy, in consultation with their stakeholders

[130] R. Vernescu, personal communication, May 24, 2007.

[131] Government of Newfoundland and Labrador, *Working together for mental health: A provincial policy framework for mental health and addiction services for Newfoundland and Labrador*, 2005.

[132] www.gov.ns.ca/legislature.legc/statutes/liquorc.htm

and informed by the provincial framework, with actions tailored to their district/shared service area.

Nova Scotia's *Alcohol Indicators Report*, an important reference for the provincial strategy, identified FASD as a significant alcohol-related harm in the province.[133] The report estimated that from 1999 to 2003, 403 babies born in that province were affected by prenatal exposure to alcohol (FASD) – approximately 81 babies a year. Of these infants, it estimated that between 54 and 161 have FAS, averaging 32 babies born each year. During that same five-year period, an average of 1.9 admissions to hospital each year was attributed to FAS.

4.2 FASD-RELATED RESEARCH

Several research studies directly pertaining to FASD and originating in the region were identified. The aforementioned paper by Smith and Rosales developed an estimate of the prevalence of FAS and ARND for Newfoundland and Labrador and summarized the FAS-related activities occurring in the province, distinguishing between primary, secondary and tertiary prevention activities.[134] The report concluded that the disorder is greatly under-diagnosed in the province, and that at that time there was an overall fair to poor awareness of FAS/FAE among professionals. The report called for more awareness raising and education on the issue and increased collaboration among interested parties.

Another FASD-specific research initiative, Attention Process Training in Young Children with FASD, was undertaken by Roxana Vernescu as a doctoral dissertation (2005-2007).[135] In light of the fact that attention difficulties are among the most commonly observed behaviours in children with FASD, this research aimed to apply a model of attention process training to improve the attention of children with a FASD. The research was conducted across two phases: the first phase consisted of a cross-over design in which six children from the St. John's area, aged 9-12.5 years with a diagnosis of FASD, received attention process training across several subcomponents of attention, including sustained, selective, alternating and divided attention; the second phase involved an experimental design in which 20 Labrador Inuit children, aged 6.8-11.9 with a FASD, received attention process training that focussed on sustained attention. An obtained abstract reported on the latter phase.

In the second phase of this study, children received either attention process training sessions that focussed on sustained attention (treatment condition) or sessions that included games and academic support (control condition). Children participated in 12 individual daily sessions of 30 minutes each, for approximately three weeks. Children completed the full assessment and treatment program over approximately five to six weeks. The treatment group showed significant gains in relation to several untrained measures of sustained attention. These gains generalized to untrained measures of

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[133] L. Graham, *Alcohol Indicators Report: A framework of alcohol indicators describing the consumption of use, patterns of use, and alcohol-related harms in Nova Scotia*. Nova Scotia Department of Health Promotion and Protection, Addiction Services, 2005.

[134] Smith et. al., op. cit.

[135] R. Venescu, "Attention process training for young children with FASD," dissertation research abstract, 2007.

selective attention and non-verbal reasoning, leading the author to conclude that this model may be a useful technique for the pediatric FASD population.

Jardine and Furgal surveyed 57 people in Nain and Hopedale on the Labrador coast on their perception of various environmental and lifestyle-related health risks and found that consuming alcohol during pregnancy was rated the most dangerous of the various risks identified.[136]

Over the past several years, the Correctional Service Canada Addiction Research Centre, located in Montague, Prince Edward Island, has been investigating the incidence of FASD in an offender population. The population being studied is located in Manitoba, and results are not yet available.

Poulin, using data from Atlantic provincial student substance use surveys, has given attention to student alcohol use, sexual activity and mental health issues in the region. As reported earlier, Poulin and Graham found high levels of unplanned sexual activity under the influence of alcohol or another drug among 15-17 year olds in the region.[137] In another study, Poulin et. al. found that, among younger adolescent girls (more so than their older counterparts), those who binge drank were at high risk of severe depression, and that this behaviour suggested a self-medicating pattern.[138] Langille and colleagues found high levels of unsafe sexual activity including unplanned sex under the influence of alcohol or other substances in a rural sample of Nova Scotia females.[139]

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[136] C.G. Jardine and C.M. Furgal, *Factors affecting the communication and understanding of known and potential/theoretical risks to health in northern Aboriginal communities. Final report submitted to the Health Policy Research Program*, 2007.

[137] Poulin et. al., "The association between substance use, unplanned sexual behaviours among adolescent students," op. cit.

[138] C. Poulin, D. Hand, B. Boudreau, and D. Santor, "Gender differences in the association between substance use and elevated depressive symptoms in a general adolescent population, *Addiction*, 2005, 100, pp. 525-535.

[139] D.B. Langille, J.R. Hughes, M.E. Delaney, and J.A. Rigby, "Older Male Sexual Partner as a Marker for Sexual risk-taking in Adolescent Females," *Canadian Journal of Public Health*, 2007, 98(2), p. 86.

5. CONCLUSION

On the basis of the documents reviewed and information synthesized, FASD has the earmarks of an emergent issue in the Atlantic Region. We estimate that 23,318 people in Atlantic Canada had FASD in 2006 at an estimated cost of $160,681,716 for care and services of persons from birth to age 64 years. While general knowledge of the dangers of using alcohol during pregnancy is high in the region, awareness of the life-long implications of FASD and the nature of partial FAS, ARND and ARBD is not so high. As is the case elsewhere, confusion around the risks associated with the consumption of moderate levels of alcohol during pregnancy is declining but remains high. This is not surprising given that the research on this question has not provided clear answers. There is no documentation on how aware people in the region are of the human toll and costs of FASD to Atlantic families and society, but awareness is likely to be low.

There also appears to be a need for greater clarity around what binge drinking means, hazards associated with it and the particular risks it holds for pregnant women. This is especially the case for young women. Current high rates of hazardous (including binge) drinking among girls in high school and university in the region, combined with high rates of unplanned sex under the influence of alcohol or other drugs, should be seen as a point of concern, both in terms of immediate harms and in terms of ingraining lifelong risky patterns.

Professional awareness and practice among health care providers appears to reflect public awareness in the region. Although general professional awareness is high, additional knowledge and training in good clinical practices appears warranted, specifically in relation to routine use of a standard screening tool for alcohol use among pregnant women, supporting alcohol-dependent women and becoming involved in diagnostic activity.

The apparent lack of FASD-specific policies in the region warrants attention. While there may be a sense that FASD children and youth can be well served by existing systems and protocols serving similar conditions, research and practice in other locales suggest this may not be completely the case – people living with FASD have unique needs that call for tailored policies and practices.

Little FASD-specific research is evident in Atlantic Canada. Given the strong academic presence in the region, an Atlantic university research agenda that gives attention to regional FASD knowledge needs may be feasible and quite valuable in advancing evidence-based FASD activity in the region.

This document review and synthesis of information provides a general profile of the nature, extent and costs of FASD; contributing factors; and the policy and research response in Atlantic Canada (note that it did not capture programming activity). The costs reported provide a strong rationale for continuing to move forward on this issue in the region. A number of issues have been raised that warrant further attention. FASD-related programming was not a part of this review, so much important work of this sort undertaken by various

individuals and organizations across the four provinces has not been accounted for. The existing literature cannot provide an understanding of the realities of addressing this issue in the region – the opportunities and challenges perceived by stakeholders. Closer examination of the current state of FASD activity in the region (including programming) will allow the Atlantic Intergovernmental FASD Partnership to begin to confidently move forward on this critically important issue in a strategic manner.

That said, while additional well-based information is always helpful to improve understanding and to inform plans, activity in the Atlantic Region should not be held hostage to the need for more information – FASD is a costly and pressing public health and social issue that calls for immediate broad, sustained commitment.

5.1 RECOMMENDATIONS

The formulation of recommendations was not an aim of this report; however, the issues discussed above warrant the consideration of stakeholders in the region. On the basis of this document review and synthesis of information, it is recommended that FASD stakeholders in the Atlantic Region consider:

1. raising awareness of the economic costs of FASD
2. raising awareness of the severity and life-long nature of FASD
3. undertaking strategic action to reduce the rates of hazardous drinking by young women
4. developing the health care provider work force on several FASD-related practices
5. undertaking strategic attention to FASD policy development
6. developing a FASD-related research agenda that includes among other priorities:
   - a general population Active Case Surveillance study to obtain a more accurate prevalence rate in the region
   - a study to determine the cost of residential/institutional and community care for individuals with FASD beyond age 21 years and justice costs for all ages.

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FORWARD, TOGETHER: ADDRESSING FETAL ALCOHOL SPECTRUM DISORDER (FASD) IN ATLANTIC CANADA

Phase II: The Report of a Knowledge Exchange Process to Identify Gaps, Opportunities, and a Vision for Activities to Address Fetal Alcohol Spectrum Disorder (FASD) in Atlantic Canada

Gary Roberts and Associates

Prepared for
Public Health Agency of Canada, Atlantic Region
and
Health Canada, First Nations and Inuit Health, Atlantic Region

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EXECUTIVE SUMMARY OF PHASE II REPORT

Phase II: The Report of a Knowledge Exchange process to Identify Gaps, Opportunities, and a Vision to Address Fetal Alcohol Spectrum Disorder (FASD) in Atlantic Canada is a report to the Atlantic Intergovernmental FASD Partnership. It presents the results of an intensive exchange exercise undertaken early in 2008 with Atlantic Canadians concerned about FASD.

Perhaps the most striking finding of this process was the great interest and passion shown by stakeholders in this issue. Respondents to both the online survey and focus sessions showed a depth of interest and concern for this issue that should be heartening to the Partnership. Participants identified in great detail the array of gaps and challenges facing the region on this issue but typically chose to interpret the situation positively, even to the extent of seeing opportunities lying behind each of these gaps.

This depth of response and positive energy led the project team to draft a vision of what FASD activity would ideally look like five years into the future according to stakeholders in the region. Heightened leadership and coordination loomed as a large part of the vision. Provincial coordinator positions were seen as a necessary foundation and investment, allowing resources devoted to this complex multi-sectoral issue to be used in the most efficient manner possible. According to the vision, priorities for provincial coordinator positions were as follows:

1. promoting the well-being of all women of child-bearing age through policy and programming that reflect a determinants of health and gender-sensitive lens;

2. promoting policy and program development for prevention;

3. fostering the formation of multi-disciplinary diagnostic teams covering ages 1-18 years through policy and program development in the health sector;

4. promoting policy and program development in the education sector to provide support and learning plan development in the elementary and secondary school system, and post-secondary planning;

5. influencing policy and program development in the community sector to support individuals of all ages with FASD (including adults) as well as their parents and families; and

6. establishing and serving as focal points for information exchange and multi-disciplinary training across the region.

The positive spirit behind stakeholder contributions should not be seen as minimizing the extent of the challenge. In some cases, respondents admitted that they were not completely certain whether gaps actually existed or whether, due to their isolation, they simply were not aware of particular activities. Nevertheless, the overall weight of the responses indicated that the gaps identified by respondents are real and wide-ranging. When asked to identify priorities across the activity areas, virtually all activity options were identified as high priority. Implicit in the range of gaps and priorities is the need for additional funding, and many respondents also stated this explicitly.

Respondents consistently called for increased leadership and collaboration at several levels, including between existing organizations and current program offerings, and among professionals such as health care workers and educators. They also want to see more cooperation at the provincial and regional levels, between communities and provincial governments, and between First Nations communities and provincial governments.

High quality, evidence-based information and professional education are priorities that cut across the activity areas. Respondents called for the development and consistent dissemination of standardized information and multi-disciplinary training. It was pointed out that coordinating these functions at the regional level (for example, through a central access point or clearinghouse) would result in efficiencies that would benefit stakeholders in all provinces and First Nations communities. Some cautioned that current information, written primarily in English, is not always culturally, ethnically, or linguistically suitable for the populations respondents are serving.

Several matters that might benefit from more exploration arose from the data. Two evidence-based measures – reducing the availability of alcoholic beverages (through taxation, etc.) and routine alcohol screening of pregnant women – were somewhat less supported by online respondents than the other options. While many areas of useful research were identified by online respondents, focus group participants ultimately viewed policy and programming to be of greater priority than Atlantic research on the issue.

Finally, it was beyond the scope of the report to break down input on a provincial basis, so it is possible that some participant comments or perceptions do not apply to all provinces.

The authors of this report conclude that it will be important for the Partnership to take advantage of strong stakeholder interest and expectations on this issue. The leadership shown by the Partnership to date was commended by stakeholders. It will be important to continue to demonstrate leadership by moving ahead strategically in a timely manner. **It is recommended that the Partnership serve as a catalyst for action on the six priorities of the vision and that it do so in the context of an enhanced regional and provincial coordination infrastructure.**

It is likely that the Partnership's success will be determined, to a large extent, by its ability to engage senior leaders of the respective governments, such as the Atlantic Assistant Deputy Ministers of Health and Health Promotion, in the months to come. FASD-specific policy in the region is virtually non-existent, and it can be argued that little of the significant change for which stakeholders have called will occur without attention to FASD-related policy at the senior or executive level. To prepare for concerted policy attention in the region, it would be helpful to identify existing policies in other jurisdictions, learn what drove the development of the policies and assess how well they are performing. **It is therefore recommended that the Partnership conduct a review and analysis of FASD-related policies within relevant departments (e.g., health, social/community services, education, justice, corrections and housing) in Canadian jurisdictions outside the region**.

In assembling knowledge of the situation in the region and seeking stakeholders' opinions on how best to move forward, the Partnership is building a solid foundation for strategic, coordinated activity. In the opinion of the authors, a measure of FASD "community building" has also occurred through this work. Without diverting energy from the first recommendation, a logical immediate step is to help stakeholders further unite into an "Atlantic Community of FASD Practice." Internet technology now permits development of sites that allow "community members" to share programs, plans and ideas using a "wiki" or open source format. Groups with shared interests are increasingly using these online sites as one vehicle (along with meetings, symposia, etc.) to promote knowledge exchange and coordinated activity.

If well managed, this kind of initiative would begin to address several prominent needs or gaps identified in this investigation. It would mitigate the sense of professional isolation

expressed by a number of stakeholders. An active community of practice would also address, at least in part, the need identified by numerous stakeholders for more coordination of efforts. It could serve as an information clearinghouse, a need mentioned by several stakeholders. Finally, it would also promote continued learning. For the most part, stakeholders demonstrated a good knowledge of the complex issues surrounding FASD, but knowledge is evolving rapidly on this issue and it will be important to stay abreast. **It is therefore recommended that the Partnership immediately begin to work with stakeholders to form an "Atlantic Community of FASD Practice" to promote shared learning and coordination of effort among Atlantic FASD stakeholders.**

1. INTRODUCTION

Phase II: The Report of a Knowledge Exchange Process to Identify Gaps, Opportunities and a Vision for Activities to Address Fetal Alcohol Spectrum Disorder (FASD) in Atlantic Canada is a report to the Atlantic Intergovernmental FASD Partnership. It presents the results of an intensive exchange exercise undertaken early in 2008 with Atlantic Canadians concerned about FASD. During the first three weeks of January, 95 persons anonymously submitted responses to a detailed online survey, providing their perspectives on gaps, priorities, and opportunities with respect to policy, programming, and research in a range of activity areas (health promotion, universal prevention, targeted prevention, intervention, support, and education and training).

As Table 1 shows, there was balanced distribution of respondents according to the province in which they worked, with all provinces well represented.

Table 1. Online Respondents' Place of Work (checked all that applied)

Answer Options	Response
New Brunswick	30.4%
Newfourdland and Labrador	18.5%
Nova Scotia	38.0%
Prince Edward Island	7.6%

Respondents were also well distributed in terms of the age range of the FASD-related clients they served either directly or indirectly. There was also diversity in terms of respondents' FASD-related work responsibilities as shown by Table 2.[10] (See Appendix B for more demographic information.)

Table 2. Online Respondents' Primary Work Responsibilities (checked all that applied)

	Response
Health Promotion	42.4%
FASD Prevention	23.9%
Women's Health	21.7%
Addictions	19.6%
Training/Education for Professionals	15.2%
Parent or Advocate	14.1%
Policy	14.1%
FASD Diagnosis/Intervention	8.7%
Research	6.5%
Other (please specify)	44.6%

Respondents were very generous with their opinions, providing a wealth of information which served as the basis of discussion for six telephone focus groups held between January 24 and February 8 (one English language session per province, plus a French language session in New Brunswick, and one session with Atlantic Aboriginal FASD workers conducted in person). Fifty people offered lively, informed input during the various focus group sessions. An overriding conclusion arising from this knowledge exchange process was that there is a widely shared and impassioned desire to move forward as a broad community on FASD issues in the region.[11]

FASD can be extraordinarily challenging, even devastating, for affected individuals and families. Yet many parents and other caregivers in time come to see that hope lies in

[10] 1. Of the 44 % who selected the "Other" category, some elaborated on the answer options (e.g., "Advocating for [First Nations] health rights at the provincial and federal levels of government"); others clarified their work setting (e.g., seven people said "family resource centre") or their roles (e.g., family physician, nurse practitioner, school counsellor, FASD trainer/facilitator, corrections officer).

[11] 2 The number of unique individuals participating in the whole process is unknown. Because respondents to the online survey were not asked to identify themselves, it is not known how many of the focus group participants also completed the online survey.

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[141]

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recognizing and building on the strengths of those affected individuals and families. They also quickly realize that help is needed from many quarters. Inevitably, there are gaps and barriers to working on this issue in the region – yet this process has shown that there are many strengths and players upon which to draw.

The next section of the report presents Atlantic Canadians' perceptions of the present state of FASD-related activity. Various gaps, challenges, and priorities are identified, presenting a picture of **"where we are."**

Section 3 discusses the opportunities – factors and circumstances – that may be leveraged to move the issue forward in the short term as identified by participants. These opportunities do not together form a strategy, but they are "strategic" in that they identify ground that is already in some way prepared and are concrete suggestions for **"how we can best move forward, together."**[142]

Section 4 presents the authors' conclusions and recommendations to the Atlantic Intergovernmental FASD Partnership on how to best build on this knowledge exchange process to advance FASD activity in the Atlantic Region.

Throughout this report, the authors have attempted to capture the positive energy that prevailed during the knowledge exchange process. Through their various written and verbal comments, participants painted a vivid picture of what needs to happen – **"where we need to go"** – to adequately address the issues in the region. Section 5 offers a vision drafted from these comments, a statement of the future to which Atlantic Canadian stakeholders aspire in terms of FASD-related activity in the region.

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[3] In Sections 3 and 4, which report on the online responses, when the term "several" is used, it indicates that three to five respondents made similar points; the term "a number of respondents" means six to nine made similar points; and "many" indicates 10 or more similar points made by respondents.

2. THE CURRENT SITUATION

The following is a distillation of the responses to questions concerning FASD-related gaps posed in an online survey and focus group sessions conducted in early 2008. The sub-sections titled Programming, Policy, and Research present findings from the online survey. Focus group participants were asked to react to the results of the online survey; their summarizing comments conclude this section on the current situation.

One of the great challenges of FASD is that an effective response calls for concerted attention to a broad range of activity areas. According to online respondents, there are programming needs in virtually all areas, and it appeared to be challenging for respondents to identify needs of particular priority. One respondent put the dilemma this way: "*Although I think the first step is prevention and health promotion by providing education to the public and to care providers, I find it difficult to grade intervention and assessment programs lower – of course they are also important and efforts for both intervention and prevention need to be happening simultaneously.*"

2.1 PROGRAMMING

A number of respondents stated that they were not aware of any programming for FASD within their geographic area (e.g., rural area, province), workplace (e.g., addictions services), area of activity (e.g., prevention, intervention, etc.), or population (e.g., women who use alcohol during pregnancy). This speaks to the fact that there are in fact few FASD services in most parts of the region, but it also reflects another factor – that some stakeholders feel isolated and unsure of what does exist in their area. Another key limitation is that FASD is currently addressed by programming that is not specific to it, such as "*individual counselling*," " *primary care interventions*," "*women's services programming*," etc.

2.1.1 Funding: Lack of funding was seen as a major impediment, with areas of particular need being funding for alternative healthy lifestyle activities such as sport and recreation events, literacy initiatives, gender-specific programming, women's centres, safe houses, programs for pre-natal families, more health care professionals, parenting programs, early detection and intervention (i.e., access to psycho-educational assessments, speech therapy, occupational therapy), outreach, and training and professional development (e.g., motivational interviewing).

2.1.2 Collaboration/coordination/partnerships: Stakeholders strongly expressed the need for a collaborative approach to the issue, noting there are groups interested in the

issue but no mechanism to bring various efforts together. Specific partnerships mentioned were between regions and provinces, between primary health care and referral services such as addiction services, and among "*communities, DHAs [district health authorities], their province and federal departments*," aimed toward fully functional provincial FASD coordination. Illustrative views of the current situation included the following:

- "*Stakeholders are often disconnected from one another and not aware of activities being carried out across the province.*"

- "*... lack of communication is frightening for programmers.*"

- "*... no central point of access to services, advice, funding, etc. which makes the system difficult to navigate.*"

2.1.3 Access to FASD services: Access to evidence-based programming and services was seen to be weak and inconsistent throughout the region both for at-risk women and FASD-affected individuals and families. Lack of access to diagnostic services was identified as fundamental by a number of respondents – as was the lack of services to respond to the diagnosis.

Barriers cited included hours, location, child care, cost, travel, literacy level, financial and geographical limitations (lack of various services in rural areas was noted by several respondents) and culture/language.

2.1.4 Public awareness: Many respondents pointed to the need for greater public awareness, identifying a range of target populations and a variety of topics, including the following:

- "*Universal messaging*" is required (i.e., messaging directed to whole populations or groups without regard to levels of risk), as well as a "*culture that supports reduced alcohol consumption by women in their child-bearing years.*" Universal messaging is needed to educate all adolescent boys and girls and young men and women about the effects of alcohol on pregnancy, for example, "*when they see their doctors about going on the pill.*" A First Nations respondent speculated that knowledge about the effects of alcohol on the unborn, as well as safe sex and responsible alcohol use, may be stronger among First Nations youth than those in mainstream communities (e.g., middle-class women; elementary, high school, and university students).

- Universal and targeted messaging must be balanced in approach (e.g., not stigmatizing or "*guilting*" women because they consumed alcohol during

pregnancy, perhaps unknowingly; mentoring higher-risk women with a "*harm reduction*" rather than a "*stop drinking blame*" approach).

- Women and their partners/families need **consistent** messages from health care providers and about the harms of drinking during pregnancy.

2.1.5 Support for substance-involved women: A number of respondents singled out addiction services as needing to be more responsive to the unique needs of pregnant women who are substance-dependent (in terms of providing specific programming and social support and in linking with other health providers). Both addiction and general services were identified as needing to do more to make women "*feel comfortable accessing and self disclosing drinking behaviours*" and to provide care for existing children while these women seek treatment. Support groups and mentoring programs for women who use substances in risky ways were mentioned as a current gap, especially support for "*a healthy pregnancy for all women*" and "*improving overall health preconception.*"

2.1.6 Screening and diagnosis of FASD: There is a need for screening that is "*effective and supportive*," as well as a "*routine assessment of all children at time of primary immunization to identify children for further assessment.*" Screening was also seen to have some drawbacks: "*... it is prohibitive to do screening that takes many documents and a great deal of time in busy clinics and care provider practices.*"

A need for access to diagnostic services was identified as fundamental by a number of respondents. It was noted that "*many children get mislabelled and therefore are being exposed to interventions that are not working.*" Diagnosis is critically important in order to properly "*assess or even begin to meet the needs of individuals with FASD.*" This fundamental gap was accompanied by a cautionary note – that diagnosis without accompanying services is not helpful and may in fact be harmful by raising and failing to meet expectations.

2.1.7 FASD-specific support for affected persons: Online respondents highlighted the need for coordinated multi-disciplinary services across the life stages. For example, "*Teachers know little about the special needs of these kids (e.g., how to handle behaviour of children with FASD) and when they do are often given little opportunity and support to plan.*" There appears to be little to no activity that supports people with FASD once they leave the school system (e.g., tailored vocational support) or their families/caregivers and those who encounter FASD individuals in their work.

2.1.8 Respite services and programs: A current gap is the lack of "*an identified agency*" to support caregivers with information/education and "*the necessary knowledge/training required to raise a child on the spectrum.*" This agency could address a range of caregiver needs, for example:

- giving attention to the children "*moving constantly within the foster care system*"

- "*services for parents as they work through issues of guilt and recovery from alcohol abuse*" and to support disclosure

- "*caregivers [need programming where they] feel listened to and that changes to meet their needs*"

- support to help caregivers "*understand the evidence and know how to ask the questions.*"

2.1.9 Interdisciplinary training and information sharing: An "*organized approach*" to training was seen to be lacking. Because so many sectors and disciplines need to be involved and working with each other, an interdisciplinary approach to training was viewed as an important current gap. A systematic interdisciplinary approach would assist in case management, addressing individuals' needs more specifically, and increase the "*capacity of service professionals to recognize and refer.*" Particular information and training gaps cited included:

- attention to the attitudes of frontline workers to support disclosure and help-seeking among substance-involved women;

- the need for "*training of diagnostic teams and other professionals,*" "*diagnostic clinics,*" and "*coordinated multi-disciplinary*" services across the life stages;

- the need for workers to be "*trained to support individuals with a diagnosis*" (i.e., people working with/encountering individuals with FASD, such as law enforcement and justice services, frontline service providers, medical personnel, teachers, child care workers, social workers, and mental health care professionals);

- lack of "*accessible knowledge base in communities*" or outside of urban areas;

- the need for cultural sensitivity in that "*staff/health care professionals [who] are not experienced working with Mi'kmaq people and within their culture ... can create barriers ... First Nations input is crucial.*" (First Nations respondents also noted that the complexity of some seminars kept participants from applying what they had learned, and English-only

program materials were viewed as "*not relevant to culture and lifestyles of Innu.*"

2.2 POLICY

2.2.1 Leadership: Respondents saw a dire need for increased commitment and leadership from provincial governments and First Nations leadership (i.e., Chief and Council), particularly addiction services, departments of health (public health and health promotion), departments of education and justice, as well as physician groups.

Provincial governments were specifically called upon to support perinatal specialty standards related to screening to make it a clinical priority in health care agencies; to increase the region's capacity for proper FASD diagnosis; to increase access to family support programs (e.g., child care programs); to provide lifelong support for those with FASD; to modify the approach to law enforcement for FASD persons; and to develop policies that reflect the realities being faced by those who are caring for FASD children and adults.

2.2.2 Coordination-related policy: Most respondents were either unaware of any policy or felt that any existing policies on their radar were not consistent, targeted specifically to FASD, or shared between organizations or levels of government. Several pointed out the need for a more "*coordinated approach*" to policy development. One respondent talked about the need to "*acknowledge the value of policy.*" Another wrote that provincial FASD strategies were needed to provide the necessary coordination.

The need for improved policy coordination was a major theme among First Nations respondents. Several indicated that their communities were "*often caught between the arguments of provincial/federal jurisdictional issues,*" resulting in First Nations communities not being able to access provincial services. They pointed out that too often Mi'kmaq children have difficulty accessing provincial services directly – instead families have to "*contract for services that should be provided as citizens of this province*". Other problems noted included "*a burdensome administrative paper trail*" that deters progress in Aboriginal communities; programs not taking the cost of living into account (e.g., Mother-Baby Food Allowance and supplements do not factor in the higher costs of food on the Labrador coast); and "*housing is often inadequate but young parents don't receive enough income supplement to access decent housing.*"

Policies are needed to "*promote coordination and sharing of information*" among various agencies and services with the aim of keeping mainstream as well as First Nations stakeholders in the region up to date on policies.

2.2.3 Specific policy needs: A number of specific policy needs were cited by online respondents:

Health promotion/prevention policies:

- holistic policies that reflect the determinants of health, such as financial issues, child care, culture, age, education, social supports, physical environments, accessibility, nutritious food, safe housing, emotional support, and subsidies for families living with FASD;

- policies that would have the effect of reducing the availability of alcohol, including increased taxes on alcohol, reduced bar hours, warning labels, alcohol monitoring systems, enforcing age limits for alcohol consumption, clear signage in liquor stores, and alcohol/drinking guidelines;[143]

- policies that reflect a move toward "*a culture of community responsibility for FASD ... in the context of other high-risk drinking practices*" rather than making it "*just a women's or First Nations issue*."

Substance-involved women:

- policies that are free of judgment or stigma and do not "*penalize*" women who use alcohol during pregnancy; policies that reflect harm reduction as a "*viable option*" since the "*reason[s] women access alcohol during pregnancy are complex*";

- policies to ensure that women are able to access programs regardless of barriers such as child care or transportation to services and promote "*empowerment*," "*security*," and "*safe environments*";

- "*clear directives for health care professionals*" that support them in responding to alcohol use during pregnancy;

- policies pertaining to pre-conception health and education, and screening as part of pre-natal care;

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[4] Interestingly, online respondents overall rated alcohol policy measures, which are strongly supported by scientific evidence, as less a priority than other measures such as public awareness campaigns and warning labels, which have a weaker evidence base.

- policies that "*address the culture of community responsibility for FASD ... in the context of other high-risk drinking practices*" rather than making it "*just a women's or First Nations issue*";

- policies that reflect gender differences and are sensitive to the needs of and support Aboriginal women and communities.

Intervention:

- Policies and guidelines are needed to support formation of multi-disciplinary diagnostic teams.

- In reference to children, a number of individuals saw specific FASD policies and services for those affected to be a priority (the program *2nd Brain* was mentioned). Affected children often do not qualify for services because they have an IQ over 70 or did not have a "*Mental Retardation*" diagnosis. Currently, there are "*continuous ongoing battles with individual schools, principals, and teachers simply because there is a lack of understanding and no 'policy' or protocol in place at the Ministerial level.*" Policies are needed to guide teachers and staff in working with these children.

- As regards adolescents and adults, attention needs to be given to developing curricula for FASD children in grades 6-12 and ensuring interventions are in place at first contact with these youth. Some respondents identified older adolescents and adults with FASD as a neglected and poorly understood population. "*Children [aged] 16-18 years ... often fall through cracks,*" and families and FASD individuals continue to live with the disorder into adulthood. For example, it was recommended that "*psycho-educational assessments and upgraded learning plans should be mandated at multiple points during a student's academic career.*" Career counselling from someone with an understanding of FASD should be available. As one respondent put it, "*they do not grow out of their disorder.*" Another respondent put it this way. "*[There is a need for] policies that take into consideration the complex, lifetime need for consistent multi-disciplinary approaches.*"

- Several respondents pointed out that departments of justice need to become more involved in policy activity regarding FASD-affected offenders, including training policy for staff.

Policy to support those caring for individuals with FASD:

- "*policies that have procedures that are easy for people to understand and follow*" and that are "*coherent.*"

Policy to guide health care and other professionals:

- policy to "*support development of multi-disciplinary diagnosis and coherent integrated service delivery*" and policy that promotes a professional environment in which standardized "*appropriate interventions are used by all.*"

2.3 RESEARCH

Some respondents stated there was a lack of Atlantic FASD research and therefore "*we do not have a clear picture of the extent of the issues.*" It was felt there was a need for a "*better understanding of what the condition really means across disciplines*" in order to coordinate and evaluate efforts in prevention, diagnosis, and intervention. "*There is a need to clarify the scope of FASD in the region and for research 'that reflects the reality' of the Atlantic Provinces; and for more understanding of the economic and social impact on families who live with a person with FASD. We have no real research into the implications of FASD for the various systems in Atlantic Canada.*" One respondent called for "*research conducted* ***and*** *generated* ***at*** *the community level.*" It was also felt that a more detailed understanding of existing programming (through environmental scans, etc.) would be useful to determine "*what services/resources are currently available.*" Other more specific comments on research needs included:

2.3.1 Public education: Suggestions in this area included "*effective ways to get the message out,*" "*how do individual populations want the message delivered,*" "*how to reach and properly diagnose women who are accessing alcohol during pregnancy,*" and "*does public awareness have any impacts on personal health practices?*"

2.3.2 Women's health: Research funds need to be directed at women's health and toward holistic studies that provide child care and financial support for families, and at socioeconomic variables that "*lead to women using alcohol – poverty, lack of child care, violence,*" as well as the "*determinants of health in women's lives.*" Respondents called for a holistic approach to FASD. For example, "*I too would like to see a more sociological approach as to why FASD persists in our communities.*" This holistic approach needs to incorporate families, foster parents, and caregivers.

2.3.3 Women's alcohol use: There remains a need for research to "*determine safe drink guidelines for women who are pregnant or planning to become pregnant,*" "*qualitative research*" with women to "*see what works/ worked to help reduce their alcohol intake,*" with "*parents/guardians who have children with FASD (they will have the best ideas),*" in remote areas and on reserve, to determine what these populations need to feel healthy, and on "*harm reduction*" and the link between self-esteem and alcohol use, with more focus

placed on the "*influence of partners' use of alcohol on pregnant women*" and not making the "*owner feel guilty.*"

2.3.4 FASD intervention and support: Research is needed to "*better define the teratogenic effects.*" Also required is research on the prevention of secondary disabilities, on suicide and FASD, the "*economic and social impact on families who live with a person with FASD,*" and the incidence of FASD persons in treatment facilities and correctional facilities. One respondent suggested that more research be conducted on alternatives to incarceration for FASD-affected offenders because judges currently are restricted to a few obvious sentencing options.

2.3.5 First Nations: One respondent stated that "*First Nations/Inuit have been researched to death.*" Another called for more research in educational interventions that are First Nations-specific.

2.3.6 Health care workers: More research is needed about health care management of "*high-risk cases,*" addressing "*inconsistent knowledge about FASD in the medical profession.*" With reference to diagnostic testing, better standards are needed regarding normal/average birth weights, head circumference, and facial appearance – especially of Innu people. There should also be more attention to the "*professional-patient relationship*" in order to increase "*understanding of alcohol use during pregnancy*" and also to "*enhance disclosure and adherence to alcohol abstinence during pregnancy and breastfeeding.*"

2.3.7 Knowledge sharing: Respondents stated that a major gap in existing research efforts was collaboration. Some felt that information existed, but that it was not organized in an accessible way, was too vast to "*keep up*" on, and that it took too long to find information. Online respondents believed there was a "*lack of connectivity*" or sharing among researchers and with community members.

2.3.8 Education and training: Respondents wanted an evaluation of current training efforts/needs. Both professionals (e.g., health care workers, teachers, child care workers, social workers, early interventionists, and community workers) and caregivers were mentioned. More research is needed with respect to education and training related to developing and disseminating effective screening tools and processes and on monitoring FASD and alcohol use.

2.3.9 Program evaluation: A number of respondents indicated that approaches need to be supported by program evaluation to measure their effectiveness, and that research should drive programming. Respondents felt that the link between research and practice should be maintained longitudinally as a means of demonstrating the impact of targeted interventions and monitoring progress on FASD issues. Some, however, did feel that there was sufficient research in this area and that it was now "*time to move on to the practical.*"

2.3.10 Best practices: A need for best practice guidelines in the following areas was identified: "*assisting/reaching women to avoid alcohol use in pregnancy or who may be at*

risk of pregnancy," "*preventing FASD and secondary disabilities*," "*interventions*," "*diagnosis*," "*treatment*," and "*overall pre-conception health*." It was suggested that the Atlantic region could review existing models for interventions, such as Washington's Parent-Child Assistance Program (PCAP), Individual Support Services Plan (ISSP), and the Newfoundland and Labrador Pathways model, and determine whether approaches used elsewhere have value in this region.

2.4 FOCUS GROUP CONCLUSIONS

All tele-focus group participants felt that the gaps in policy, programming, and research identified through the online survey were an accurate reflection of how things stand in their respective provinces. They did feel that addressing gaps in research was less a priority than addressing the gaps in policy and programming. The thinking was that there was research going on elsewhere that, if tracked and shared, would contribute greatly to the understanding of FASD policy development and service delivery in Atlantic Canada. The need for policy and programming was seen as simply too urgent to wait for Atlantic research.

The policy and programming gaps perceived to be most pressing by the tele-focus groups were as follows:

- Leadership (from policy makers) and better coordination of effort are extremely important.

- The development of policies within key government departments needs to draw attention to FASD as an area requiring a specific focus, framing gaps in terms of specific policies so that governments can respond. The point was made that governments see themselves in the business of developing policy and that when gaps are presented in terms of policy it is easier for governments to recognize their role.

- There is a need to approach prevention from a social determinants of health and gender perspective so that the lived experiences of substance-involved women are reflected. It is also important to recognize the responsibility of men involved with women who may drink during pregnancy. Particular attention needs to be paid to women who may drink before they know they are pregnant and to young men and women whose alcohol use is paired with unplanned and unprotected sexual activity.

- Front line health workers including family physicians and nurses have a vital role to play in prevention and in early intervention. More attention needs to be paid to making sure they are well-educated and informed, know the latest research on alcohol and pregnancy, and know how to respectfully intervene.

- Schools need protocols for responding to children who appear to have FASD symptoms, whether formally diagnosed and assessed or not.

- Each province needs access to a multi-disciplinary team (paediatrician, psychologist, physical therapist, speech-language pathologist, occupational therapist, social worker, etc.) that can assess children from birth with regular follow up to identify and respond to developmental changes through adolescence and adulthood.

- An assessment capacity needs to be developed for adults with FASD who may not have been diagnosed during childhood.

- The presence of community or provincial level advocates who are willing to push things forward, with or without government support, is uneven across the region. There needs to be a way to reach and support parents so they can begin to advocate for change.

3. GETTING STARTED – OPPORTUNITIES FOR MOVING FORWARD

Participants in the knowledge exchange process identified an array of gaps that need attention. However, they also presented a number of opportunities – circumstances or initiatives – that could help stakeholders get started.

3.1 OVERALL

At least in some parts of the region, there is a sense of growing awareness of the issue within key government offices, with FASD increasingly being included in discussions. It was noted that the Atlantic Provinces have some shared features (e.g., large rural populations) so a regional approach makes sense and should be more efficient. The region also has the benefit of the experience of the Western Provinces to guide its approach obviating the need to create a new "Atlantic wheel" or to create policies from scratch. At the same time, it was noted that much local expertise and existing programs could be learned from and built upon.

3.2 POLICY DEVELOPMENT

The Nova Scotia Provincial Alcohol Strategy is an example of a larger strategic or policy-oriented initiative that is specifically addressing FASD. Launched in August 2007, the strategy aims to reduce harmful drinking, including prenatal alcohol use. The Nova Scotia Department of Education is participating in some of the activities of the Alcohol Strategy and the consultations and workshops supporting its development. The Department recognizes the need to offer specific support appropriate for students with signs of FASD to maximize their educational potential. New Brunswick recently held a think tank on FASD; the province has a new health policy around addictions and is looking at including an FASD strategy as part of a drug and alcohol strategy. As one respondent put it, "*There seems to be an increase in political will to address FASD in [New Brunswick].*"

Several respondents proposed that the Atlantic Intergovernmental FASD Partnership move ahead on FASD-related policy by facilitating a collaborative approach to policy development, bringing together policy makers/high-level government officials to approach policy review and formulation in a systematic manner (through, for example, task groups or regional fora), thereby cutting down on time and confusion.

Other points:

- Include an FASD component in the child and youth strategy being developed in Nova Scotia.

- Engage with the Nova Scotia Social Policy Committee concerning programs and services for youth.

- Take advantage of current government reviews, such as in the area of early intervention, to address FASD policy issues.

- With a better understanding of the costs linked to FASD, it will be possible to put together a business case for addressing FASD in the region.

- Use the momentum from this project to put a task/work group together to identify key policy development needs and where policy already exists, publicize it.

3.3 COORDINATION

Many respondents indicated that it was crucially important to take advantage of all opportunities to promote collaboration. The region has a history of collaboration among the provinces; some FASD-related activities (e.g., regional coordination, shared training, media purchasing) may particularly benefit from shared effort. Other points shared by respondents:

- New Brunswick has funded an FASD coordinator to review the current situation in the province, work on best practices and help move toward the development of a service delivery model.

- In New Brunswick, several communities have their own FASD committees, and the members work to share information and coordinate activities and services.

- Nova Scotia recognizes the need for coordination and is moving towards this through its Alcohol Strategy. There is also an FASD stakeholder forum planned to set the agenda for moving forward on the issue.

- St. John's has a local FASD committee including parents (but it needs more support to be able to continue to meet and work).

- There are already a number of current programs under way in the region, and a review of these initiatives would enable the FASD community to more fully determine areas not being covered.

3.4 PREVENTION

It was pointed out that many organizations are concerned with the determinants of health and universal prevention and that FASD stakeholders could link with and support these efforts for mutual benefit. The strong work and of existing community organizations and services, such as the Canada Prenatal Nutrition Program (CPNP) and the Community Action Program for Children was noted.

Other points:

- New Brunswick is giving more attention to FASD-related alcohol policy issues.
- Nova Scotia Literacy has 300 learning centres and if a basic FASD learning resource were available, it could be used in these programs.
- Local libraries sponsor displays and information sessions and would be open to FASD as a topic.
- Prince Edward Island conducted a campaign involving the liquor commission as a partner during which information on alcohol and pregnancy was shared. Lessons were drawn that might be used with a new campaign. In that regard, it was suggested that the school program supported by the Manitoba Liquor Commission be investigated and a similar partnership in this region be explored.[144]

3.5 INTERVENTION AND SUPPORT

The Public Health Agency of Canada's national guidelines on diagnosis were seen as an important step in providing guidance on diagnosis and assessment. Family resource centres such as Maggie's Place (Amherst and Truro, Nova Scotia), other Community Action Program for Children (CAPC) projects, and CPNP projects, including Healthy Baby Clubs in Newfoundland and Labrador, were seen as being well established in their communities and doing "*great work*." Such services were seen as excellent examples to draw upon and places to build FASD-specific programming for women and families. The work of the Gender and FASD Project developed by the Public Health Agency of Canada and CAPC/CPNP/AHS was seen as providing an excellent base for training in the larger community.

In Nova Scotia, the Department of Education was seen as an ally in terms of advancing the state of educational services for FASD children. It was noted that student service coordinators meet four times a year and have made it a priority to find more research on secondary FASD characteristics to inform their program planning process.

It was suggested that the FASD training program developed by the Federation of Foster Families in Nova Scotia be reactivated, updated and made available to foster parents.

144 [5] It should be noted that the involvement of liquor commissions/corporations in FASD-related campaigns is controversial and not supported by all stakeholders.

3.6 EDUCATION/TRAINING/INFORMATION SHARING

The best practice guideline development and other national training and knowledge exchange initiatives commissioned by the Public Health Agency of Canada and the Canadian Centre on Substance Abuse were seen as important tools for the region. Online technologies that are becoming increasingly affordable and accessible were seen as a useful option for addressing FASD training needs in the region. It was noted that the health profession and social work faculties at Nova Scotia's Dalhousie University (and other universities) routinely bring in a variety of professionals to speak to the students on special topics, and that FASD needs to become a regular focus of these programs.

One respondent mentioned a training policy that was noteworthy and possibly worth replicating: "*We will not train a police agency unless an equal number of community partners are also in attendance for the training. If there are ten police officers then there must also be ten others such as a judge, defense counsel, legal aid, social services, etc. also committed to attend.*"

3.7 RESEARCH

Several survey respondents pointed out that there are a number of institutions in the Atlantic Provinces, such as universities, community colleges, hospitals, and alcohol and gaming corporations, that could drive, support, or collaborate on research. The feeling was that "*we have an abundance of strong universities with top-notch research facilities and resources that can be utilized.*" One participant suggested that sponsoring research chairs at post-secondary institutions might increase emphasis on FASD. This could be accomplished under the Canada Research Chairs program. Existing experts in the area (e.g., Ted Rosales, Nicole LeBlanc, Lori-Vitale Cox, William Vitale-Cox, and others at the IWK Hospital in Halifax) were identified as individuals capable of "*steer[ing research] in the direction of 'concerns that would be specific and peculiar to Atlantic Canada.*' "

Fetal Alcohol Research, the journal of Fetal Alcohol Canadian Expertise (FACE), was seen as providing a valuable focal point for Canadian research. One respondent indicated that existing provincial databases on pregnancy could be enhanced if health practitioners were trained on how to ask about and document alcohol use during pregnancy. These databases could then be "*link[ed] to other health and social databases to inform research and to get a better picture of FASD in [Nova Scotia].*"

It was suggested that Atlantic stakeholders be alert to opportunities to augment or expand on national surveys, databases, and reference services commissioned by national bodies such as the Public Health Agency of Canada, Health Canada, and the Canadian Centre on Substance Abuse, for the benefit of the region.

4. CONCLUSION AND RECOMMENDATIONS

It is said that FASD can be overwhelming to deal with at the personal level. At the strategic level, the number of areas calling for attention can be similarly overwhelming. This project broke down FASD-related activity according to policy, programming, and research with regard to health promotion, universal and targeted prevention, intervention (including diagnosis and assessment), support, and education and training. In the Atlantic region, where strategic attention to the issue is relatively new, it should not come as a surprise that stakeholders identified a considerable number of gaps, challenges, and priorities across these various activity areas. There is clearly much to be done. The very good news is that – judging by the response to this knowledge exchange process – stakeholder interest is very strong.

Moreover, when given the opportunity to discuss the issues, focus group participants were sufficiently consistent in their thinking to allow for the development of a vision to be drafted by the authors, proposing several priorities for the region:

1. promote the well-being of all women of child-bearing age through policy and programming that reflect a determinants of health and gender-sensitive lens;

2. promote policy and program development for prevention;

3. foster the formation of multi-disciplinary diagnostic teams covering ages 1-18 years through policy and program development in the health sector;

4. promote policy and program development in the education sector to provide support and learning plan development in the elementary and secondary school system, and post-secondary planning;

5. influence policy and program development in the community sector to support individuals of all ages with FASD (including adults), as well as their parents and families, and;

6. establish focal points for information exchange and multi-disciplinary training across the region.

The vision proposes these priorities in the context of enhanced coordination, both regionally and provincially. It is possible that progress could be made on these priorities without stronger regional and provincial coordination, but it is questionable. As realized in other jurisdictions, the complexity of the issue and the multiplicity of actors demand a coordinated and collaborative approach. Strong regional and provincial coordination would ensure that existing resources are used most efficiently and provide the necessary infrastructure for ongoing strategic planning and action. It is likely that a strong business case can be developed, arguing that an investment in proactive coordinated attention to

FASD will avoid many of the significant economic and social costs associated with the issue.

Stakeholders applauded the leadership of the Atlantic Intergovernmental FASD Partnership. They called for a continuation and strengthening of this leadership. **It is therefore recommended that the Partnership continue to lead by serving as a catalyst for action on these six priorities, in the context of an enhanced regional and provincial coordination infrastructure.**

It is likely that the Partnership's success will be determined, to a large extent, by its ability to engage senior leaders of the respective governments, such as the Atlantic Assistant Deputy Ministers of Health and Health Promotion, in the months to come. FASD-specific policy in the region is virtually non-existent, and it can be argued that little of the significant change for which stakeholders have called will occur without attention to FASD-related policy at the senior or executive level. To prepare for concerted policy attention in the region, it would be helpful to identify existing policies in other jurisdictions, and to learn what drove the development of the policies and assess how well they are performing. **It is therefore recommended that the Partnership conduct a review and analysis of FASD-related policies within relevant departments (e.g., health, social/community services, addictions, education, justice, corrections, and housing) in Canadian jurisdictions outside the region.**

In assembling knowledge of the situation in the region and seeking stakeholders' opinions on how best to move forward, the Partnership is building a solid foundation for strategic, coordinated activity. In the opinion of the authors, FASD "community building" has also been stimulated by this work. Without diverting energy from the first recommendation, a logical immediate step is to help stakeholders further unite into an "Atlantic Community of FASD Practice." Internet technology now permits development of online sites that allow "community members" to share programs, plans, and ideas using a "wiki" or open source format (some of which is freely available). Groups with shared interests are increasingly using these online sites as one vehicle (along with meetings, symposia, etc.) to promote knowledge exchange and coordinated activity.

If well managed, this kind of initiative would begin to address several prominent needs or gaps identified in this investigation. It would mitigate the sense of professional isolation expressed by a number of stakeholders. An active community of practice would also address at least in part the need identified by stakeholders for more coordination of efforts. It could serve as an information clearinghouse, a need mentioned by several stakeholders. Finally, it would also promote continued learning. For the most part, stakeholders demonstrated a strong understanding of the complex issues surrounding FASD, but knowledge is evolving rapidly on this issue and it will be important to stay abreast. **It is therefore recommended that the Partnership immediately begin to work with stakeholders to form an "Atlantic Community of FASD Practice" to promote shared learning and coordination of effort among Atlantic FASD stakeholders.**

5. THE VISION

The year is 2013. It has been five years since the completion of ***Forward, Together: Addressing Fetal Alcohol Spectrum Disorder (FASD) in Atlantic Canada****. As part of its knowledge exchange process, a vision for FASD activity in the region was developed. The following is a presentation of what a report by the four provincial FASD coordinators from Atlantic Canada describing the state of FASD-related activity in the region could look like in five years' time.*

A first step in building a responsive and comprehensive FASD service network in Atlantic Canada began with a concerted effort to encourage coordination across relevant government departments (health, community services, addictions, education and justice). Coordination at the departmental level was seen as essential for the growth of policy and programming that could both prevent FASD and address it across the lifespan. Importantly, it was recognized that coordination could not happen without a strong focus on the issue and dedicated personnel working on it. Consequently, each province has been funding an FASD coordinator position for several years through a cost-sharing agreement among several departments. Initially, provincial departments of health, community services, and education came on board, with departments of justice joining the coordination effort a bit later as they recognized the numbers of individuals within the system with suspected FASD. The Public Health Agency of Canada and Health Canada provided a regional coordination function from the outset.

The provincial FASD coordinators collaborated and agreed upon six initial regional priorities:

1. promote the well-being of all women of child-bearing age through policy and programming that reflect a determinants of health and gender-sensitive lens;

2. promote policy and program development for prevention;

3. foster the formation of multi-disciplinary diagnostic teams covering ages 1-18 years through policy and program development in the health sector;

4. promote policy and program development in the education sector to provide support and learning plan development in the elementary and secondary school system, and post-secondary planning;

5. influence policy and program development in the community sector to support individuals of all ages with FASD (including adults), as well as their parents and families; and

6. establish and serve as focal points for information exchange and multi-disciplinary training across the region.

To date, these are some of the accomplishments:

- Each province has made significant progress in the development of policies across departments that give specific attention to health promotion, FASD prevention, identification, and intervention.

- A key concern as we began our work was the need to cultivate a new perception of women's health and use of alcohol. It was by no means simple (and there is much yet to do) but we understood we needed to arrive at a consensus within the Atlantic FASD community on how women's health needs to be viewed in order to advance health promotion and prevention of FASD:

  - women's use of alcohol needs to be seen more broadly than in the past – young people, male partners, middle- and high-income women are among those who needed to better understand their stake in the issue;

  - substance-involved women need to be de-stigmatized, their lives need to be better understood by service providers and society generally, and messages and services directed to women need to reflect a respectful, non-judgmental attitude;

  - women's health would no longer be considered important and worthy of attention only at the time of pregnancy to ensure fetal and child health; society would be concerned for and proactive on women's health for a variety of health and economic reasons, including ensuring fetal and child health.

- Agreement on these principles led to three major prevention policy and programming successes:

  - a jointly funded and developed public education and awareness campaign was launched across the region with messages designed for key audiences, including young men and women who are sexually active and use alcohol hazardously, families of women of childbearing age, and women of childbearing age;

  - evidence-based routine screening has been put in place for all pregnant women, with plans to extend to all youth and adult patients in the family health care systems;

- a strong effort is under way throughout the region to ensure a continuum of care for pregnant women shown to be at risk through routine screening (including brief and longer-term treatment).

- The other provinces followed Nova Scotia's lead in the launching of an alcohol strategy, which provided context and impetus for FASD prevention efforts.

- Multi-disciplinary diagnostic teams have been established in Nova Scotia and New Brunswick. Key individuals have been identified and trained in Newfoundland and Labrador and Prince Edward Island and work with the multi-disciplinary teams to provide service through tele-health and rotating clinics in rural and remote areas.

- An extensive outreach program has connected with family physicians, nurse practitioners, and social workers to extend the ability to make appropriate referrals to the diagnostic teams.

- On the intervention front, one of the first activities of the FASD coordinators was to reach out to parents of children with FASD and consult with them on the range of their support needs as well as the type of support they felt worked for them.

- Education policies specific to FASD have been introduced as part of a holistic approach to learning disabilities encountered in the school systems.

- A range of community-based programs has been put in place to respond to the needs of FASD individuals and the families who support them, across the life span and across all aspects of life (education, employment, and independent living). In most cases, this has involved expanding the capacity of existing community services through human and funding resources so they can meet the needs of a range of clients.

- An online resource clearinghouse has been put in place for the four provinces. It includes information on research, program evaluation, best practices, a program inventory, key advocates, and networking vehicles for those working in the field who wish to be connected with their peers. The information aims to serve parents and families as well as service providers. The clearinghouse also provides a focus for annual International FASD Awareness Day activities in the region and an annual Atlantic Canada information-sharing conference with sessions for parents and for service providers.

- Training to identify individuals with suspected FASD and to make appropriate referrals and responses has been integrated into university and community college systems (e.g., social work, teacher education, medicine, etc.) and ongoing training is available through professional in-service.

- A universal training package has been developed to equip stakeholders with core competencies to address issues across the spectrum of FASD services. This standardized tool kit contains basic information about FASD for public, professional, and parents/caregiver use.

- Monitoring and surveillance systems have been enhanced, permitting more regular updating of data on alcohol use and sexual activity among high school students, a better understanding of the number of women at risk for delivering an alcohol-exposed child, and much better documentation concerning persons with a FASD in the region. Encouragingly, we are starting to see a decrease in alcohol-related unplanned sexual activity among high school students.

It has not been easy to get to this point. Neither substance-involved women nor individuals with FASD are homogenous groups that can be supported with a single program. For this reason, the approach has been to integrate knowledge about FASD prevention and intervention into existing service networks and to expand their ability to meet the needs of substance-involved women and FASD clients.

We also have had to develop a clear road map for getting started and staying on track. Above all, we wanted to make sure our actions were sustainable. To do this, we consciously paid attention to the values, structures, and processes that we were using to identify and implement our strategy, policies, and programs. We considered how each step would affect the people it was intended to support, the underlying values reflected in the proposed actions, and the presence or absence of structures that could support whatever actions we were considering. This has helped us to be realistic in what we were and were not able to achieve and to avoid actually harming the people for whom the FASD network was intended.

6. APPENDIX A: PROJECT BACKGROUND

6.1 CONTEXT

In 2000, the Atlantic Intergovernmental FASD Partnership (formerly the Atlantic Intergovernmental Committee on FASD) was formed. The Partnership is comprised of representatives from each of the four Atlantic provincial governments:

> New Brunswick: Department of Health; Family and Community Services; River Valley Addiction Services
>
> Nova Scotia: Department of Health Promotion and Protection, Public Health and Addiction Services; Department of Education; Department of Community Services
>
> Prince Edward Island: Health and Social Services; PEI Reproductive Care
>
> Newfoundland and Labrador: Department of Health and Community Services, Prenatal and Early Childhood Development and Addiction Services; Eastern Health; Nunatsiavut Department of Health and Social Development.

Representatives from federal government departments are the Public Health Agency of Canada, Health Canada (First Nations and Inuit Health), and the Correctional Service of Canada. The Partnership provides a forum for federal, provincial, and regional partners to collaborate and address the issue of FASD in the Atlantic Region. In 2007, the Partnership documented what is known about FASD in Atlantic Canada in terms of incidence, prevalence, costs, policies, and research. That work was the basis for this current investigation of stakeholders' perceptions of gaps, opportunities, and priorities concerning FASD in Atlantic Canada.

6.2 AIM

This project comprised a knowledge exchange process with stakeholders in the region to gather the following information:

- detailed findings on gaps and opportunities in policies, programming, and research related to FASD initiatives (prevention, promotion, intervention, support, training/education, and screening/diagnosis);
- existing federal and provincial policies relevant to FASD;
- FASD research initiatives with an Atlantic or provincial-level analysis (including those involved); and

- an analysis of findings and recommendations for future directions for the Atlantic Intergovernmental Fetal Alcohol Spectrum Disorder Partnership.

6.3 METHOD

6.3.1 Step 1: This project built on *Forward. Together: Addressing Fetal Alcohol Spectrum Disorder (FASD) in Atlantic Canada. Phase I: Document Review and Synthesis of Information on Fetal Alcohol Spectrum Disorder (FASD) in Atlantic Canada.* At this time, a list of more than 100 stakeholders, or individuals with an interest in FASD, from the Atlantic Provinces were compiled into a database. This list was used to contact stakeholders for the current initiative, the FASD Atlantic survey.

The survey was created and mounted on *SurveyMonkey*, an Internet-based survey tool. Stakeholders were contacted via email. The email explained the purpose of the survey, gave backgrounders on the issues, and provided a link to the online survey. Data collection took place over a three-week period from January 3 to January 25, 2008. In addition to the original email, three reminder emails were sent. There were some problems with our methodology in that there were approximately 20 delivery failures. We made every effort to locate the correct emails for these individuals with the help of the Partnership. A small number of individuals completed the survey by hand rather than online, and their data were inputted into *SurveyMonkey*.

The survey consisted of 10 screens and solicited the following information: demographic data and respondents' input on programming, research, and policy initiatives. Respondents were also asked to share their "top priorities" overall. The survey consisted of short answer questions ("check all that apply") and open-ended questions. The survey included a progress bar at the bottom of the screen so that respondents would know where they were relative to the beginning and end of the survey.

Open-Ended Questions: Respondents were asked to comment on policy, programming, and research issues related to the key areas of health promotion, universal and targeted prevention, intervention, support, training, identification, and diagnosis. However, our initial plan to report the results according to these categories was altered after an examination of the data. Survey respondents discussed more than just these areas; their passion for the issue of FASD led the consulting group to consider another means of exploring and sharing the data. The synopsis of the survey data is organized according to:

1. Where do we want to go? In other words, what is the ideal system for coordinating and leading FASD initiatives and efforts in the Atlantic Region?
2. What is the current status in the region?
    a. What is currently missing?
    b. What are existing opportunities in the region ?
3. What recommendations do we have for the Public Health Agency of Canada based on the results of this survey?

6.3.2 Step 2: Step 2 of the process consisted of a series of provincial tele-focus groups convened with the stated aim of helping to interpret the Step 1 data. The tele-focus groups were scheduled for 11am -12:30 pm (local times) on the following dates:

New Brunswick (English): February 4
New Brunswick (French): February 5
Prince Edward Island: February 6
Newfoundland and Labrador: February 7
Nova Scotia: February 8

An in-person Aboriginal focus group meeting was scheduled for January 24 in Charlottetown, involving staff from 10 First Nations community FASD projects.

All stakeholders were invited to register for a focus group. Groups were limited to 12 participants (no province received more than 12 expressions of interest). Data on respondents' opinions of the gaps, opportunities, and priorities with respect to each of the activity areas were drawn from Step 1 and summarized and distributed to participants prior to the focus group sessions. The data from the online survey served as the basis for "bigger picture" discussion concerning gaps, opportunities, and priorities.

To help recruitment and out of respect for participants' time, the sessions were limited to 60-90 minutes. The provincial focus groups elicited the collective insight of a range of professionals and one parent in response to the policy, programming, and research gaps and action priorities identified through the online survey. The focus group participants endorsed the portrait presented through the online survey. However, their animated and frequently optimistic conversation presented an additional picture – a picture of what a responsive FASD service network in Atlantic Canada might look like. They also illustrated what is currently missing and the elements in place to start building their vision of a response network.

It needs to be emphasized that the vision statement presented in this report is not the product of a formal consensus-building exercise involving stakeholders – it is an attempt to fairly present the opinions of Atlantic stakeholders and to capture the positive energy prevailing through the knowledge exchange process.

7. APPENDIX B: KNOWLEDGE EXCHANGE PARTICIPANT INFORMATION

7.1 ONLINE SURVEY RESPONDENT DEMOGRAPHIC INFORMATION

A total of 95 FASD stakeholders responded to the online survey. It is important to note that not all stakeholders answered every question.

The provincial breakdown of respondents' place of work was as follows: Nova Scotia (38%), New Brunswick (30.4%), Prince Edward Island (7.6%), and Newfoundland and Labrador (15.2% – 13% and 2.2% respectively). In a few cases, respondents worked in more than one province.

Respondents worked with a range of age groups, from infants to early childhood (69.6%), children ages 7-12 (31.5%), adolescents (47.8%), and adults (72.8%).

Participants were asked to describe the linguistic or cultural make-up of the populations with whom they worked. Many stated that they worked with English (83.5 %) or Francophone (33%) communities. A number of Aboriginal groups were also represented including: Innu (14.3%), Inuit (16.5%), Mi'kmaq (37.4%), Maliseet (13.2%), and Métis (9.9%). Other populations included immigrants, women, and African Canadians.

What populations do you serve (check all that apply)?		
	Response Per Cent	**Response Count**
English	83.5%	76
Acadian Francophone	33.0%	30
Aboriginal: Innu	14.3%	13
Aboriginal: Inuit	16.5%	15
Aboriginal: Mi'kmaq	37.4%	34
Aboriginal: Maliseet	13.2%	12
Aboriginal: Métis	9.9%	9
Other (please specify)	12.1%	11
skipped question		**4**

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Other (please specify)	12.1%	11
answered question		91
skipped question		4

Is the focus of your work with (check all that apply)?		
	Response Per Cent	**Response Count**
Children (ages 0-6)	69.6%	64
Children (ages 7-12)	31.5%	29
Adolescents	47.8%	44
Adults	72.8%	67
skipped question		**3**

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skipped question		3